

## **THE NARRATIVE PLAYBOOK:**

*The Strategic Use of Story to  
Improve Care, Healing, and Health*



## ***“I usually have this on my key chain.*”**

It's a World War II dog tag for a man named Perry Dunham, who was born in 1919 in Caro, Michigan, a very small town in the “thumb” of Michigan. I'd love to tell you he was a war hero, but he wasn't. He liked to brag that he signed up for Army right after Pearl Harbor because he didn't want to be drafted. Which says a lot about his personality; he liked to be in control. He served stateside — in California and Alaska — as a meteorologist. He was discharged before the end of the war, graduated from college, married three times (twice to the same woman), and had four daughters — two per wife. He joined Ford and then rose through executive leadership ranks throughout the 70s, finally settling in Wisconsin and starting his own headhunting business, finding physicians for hospitals. He had 40 acres of land, a beautiful house, a beautiful wife, and two adolescent daughters.



He also had lung cancer, something he found out in May 1980. Six months later, the doctors told him his cancer had spread to his liver. Three months after that, he was gone.

That man was my father. I watched him go from an irascible, brilliant, in-control man who helped run companies and loved to say “lead, follow, or get the hell out of the way” to a shell of a man who couldn't write his name, read the paper, or walk up a flight of stairs. It was one of the most painful experiences of my life.

I tell you this because my father's experience had me avoiding hospitals religiously — aside from giving birth to my children — for more than 25 years. In college, I majored in theater, then switched to journalism when I realized I couldn't act, and worked in communications for many years — even working for healthcare systems.

Then I decided to go to nursing school.

I discovered two things. Becoming a nurse allowed me to help others like my dad, which in some way made up for my not being able to ease his suffering. And, after rarely talking about the experience of his loss for 20 years, I began to write about it. And in the writing, I found healing.

I started paying attention. I moved to the Robert Wood Johnson Foundation, and started meeting and learning about people who had known all along what I had just learned: Storytelling is healing. Storytelling also builds bridges. Between patient and family. Between patient and healthcare provider. Between patients.

For two years, I've been kicking around this idea: What if we could bring these storytellers together in one place? Could we use that gathering to create tools and think about ways to make storytelling — in all its forms — an integral part of the way we “do” healthcare?

What transformative power it could have! Creating a sense of dialogue in a field that is often polarized, giving patients real power, hearing and acting on their perspective. Helping clinicians “listen between the lines” — capturing clues no blood pressure cuff or stethoscope could.

That's why we developed this narrative playbook. We believe it has the potential to not only raise awareness of the value it can bring to healthcare, but also to increase the spread of innovation and learning in this field — and, ultimately, we hope, practices that can improve care, healing, and health outcomes for everyone.”

*Beth Toner*

*Senior Communications Officer*

*Robert Wood Johnson Foundation*

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# INTRODUCTION



Our healthcare system has made tremendous advances in the past few decades — advances that have also created very real challenges. Technological advancements, such as Electronic Health Records (EHRs) have created opportunities for collaboration — but for some, have also come with a heavy burden of transition from the comfortable, age-old medium of pen and paper. Some of the blessings that accompany advances in medical devices or research practices also come with newfound risks or ongoing political or moral debate. There is much more to medicine than technology, drugs, and machinery. Healthcare is about people, and involves the whole person: body, mind, and spirit.

There is a concurrent shift in healthcare today, toward a more human-focused system in which the patient has a face and a story as well as a chart and a white blood cell count. This approach has long been practiced by artists, performers, poets, and writers. This approach has also been explored by physicians, nurses, administrators, and other healthcare stakeholders. It has been championed by patients and caregivers — those who need to find their voice in the healthcare system. This human-focused approach acknowledges that curing and healing are not always the same; one can be healed without being cured, and one can be cured without being healed.



Narrative and story is already pervasive in our lives as well as in healthcare. Hospitals, nursing homes, therapy facilities, and other health-related organizations are filled with stories simply because they are filled with people — not just the patients, but all the people involved in their care.

However, this shift to a human-centered approach has been happening in fragmented efforts and separate silos. To truly make an impact, we must connect these fragments and silos. This playbook is just the beginning of that effort.



## **HOW THE PLAYBOOK** *was* **DEVELOPED**

We gathered 30 healthcare thought leaders to co-create what you are reading today. These thought leaders came from varied backgrounds — researchers, educators, practicing clinicians, and artists — all with a passion for transforming healthcare. Our group also included patients who have found peace and healing through story. The wisdom the group shared, as well as the narrative healthcare case studies we have gathered, provided us the knowledge and momentum to produce this book.

We hope readers who already use narrative methods will feel they're part of a valuable movement in healthcare. We hope readers who are new to narrative practice will feel empowered to try it. We hope narrative reaches into all areas of healthcare, improving care teams and facilities, engaging care providers, and empowering patients and caregivers.

Our goal with this playbook is to identify where in healthcare narratives can occur, and to provide “plays” or strategies for harnessing the power of story for improved care, healing, and health.





*what is*

# **NARRATIVE AND STORY?**



## **DEFINING NARRATIVE**

The word “narrative” means different things to different people. Perhaps, to you, it refers to literature or a long-winded analysis. Or perhaps it means nothing to you. Similarly, the word “story” may bring to mind ogres and princesses lost in the woods; a sequence of events with a beginning, middle, and end; or perhaps a full account of someone’s life.

In some cases, the terms “narrative” and “story” can be interchangeable, while in others they differ. However, the truth is that in healthcare, we have drifted far from valuing either of these concepts. Yet they are an important way, perhaps the only way, to provide much-needed context that can help create a new perspective or provide an important clue. Even more important, story and narrative can emotionally connect the clinician or caregiver to the patient in ways that can better guide a treatment or care plan.



We consider “narrative” to be bigger than story. A narrative includes stories within stories, all of which help us make sense of our complex lives. Narrative is constantly changing. Throughout our daily experiences, the evolving stories that make up our narrative provide the common thread that allows us to incorporate new information into our understanding.

So when we use the term “narrative,” we refer to the many stories that make up one’s own personal history. Narrative is the web of which each story, each tale told, is one strand.



## the **POWER OF NARRATIVE** and **STORY**

To us, the natural act of narrative is a universal tool that enables us to discover and reveal stories that might otherwise be lost, invisible, or dormant. Through stories, we can reveal our conscious attitudes, thoughts, emotions, wishes, or aspirations, as well as discover our unconscious motivations, values, intuitions, beliefs, and fears. Our stories can be discovered and told through different mediums, including written, oral, and artistic mediums. We can reveal what we've discovered internally to ourselves, or externally to others.

Narrative creates different discovery opportunities. Narrative describes, extracts, reflects, connects, and makes a point. Narrative allows us to shape our stories into a whole — building, sharing, listening, interpreting, and (re)framing.

At its best, narrative creates resonance, understanding, humanity, empathy, caring, meaning, connection, context, recognition, respect, and harmony.

Conversely, when narrative is *missing* from healthcare, the result is often confusion, misinterpretation, dissonance, emotional abandonment, missed signals, resentment, and withdrawal.



*how to use this*

# **PLAYBOOK**



Story supports healing and care for everyone involved in healthcare. Patients need stories to create an ongoing narrative to help them make meaning of, come to terms with, and understand their health challenges and triumphs. Caregivers need stories in a coherent narrative to improve their capacity to navigate the healthcare system on behalf of their loved ones — and care for themselves. Meanwhile, healthcare providers who understand that narrative reveals the human context of their patients are able to provide more holistic care.

We've built this playbook to be practical and flexible for each person's needs and contexts. Here's how you can use it:

**FIRST**, you can browse the **COLLECTION OF METHODS** to explore how narrative can be used in different ways. Curious about journaling? Interested in expressive arts? We've provided activities and corresponding worksheets to help you explore how narrative can improve care, healing, and health.



**SECOND**, you can flip to the section that best applies to you —

**PATIENT**, **CAREGIVER**, or **PROVIDER\***.



Within these sections, you'll find targeted suggestions for methods you can use in different situations, including:

- Day-to-day living
- Feelings of frustration
- Difficulty dealing with a diagnosis
- Feeling isolated and disconnected from others
- Feeling stressed or hopeless

We also encourage you to explore the whole playbook. You'll find many practical suggestions for ways to use narrative and story in healthcare, enough to help all—patients, caregivers, and providers—get started.

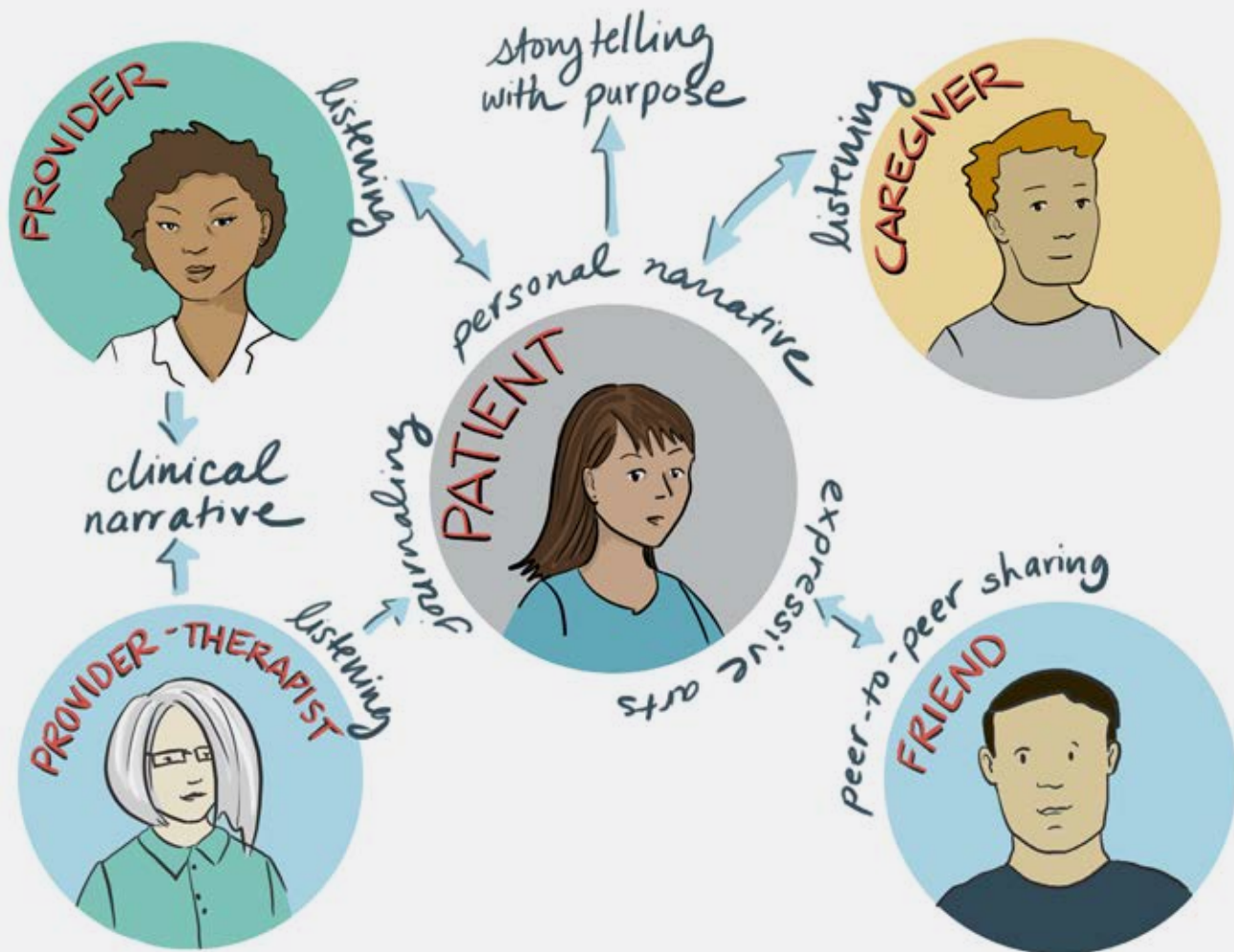
### **INTERACTING WITH THE PLAYBOOK**



Throughout this Playbook, you will see icons, links, and various buttons to click on that will take you to related materials. If you get lost, the **compass on the left** will take you to the Contents page. If you go to a link and would like to return to where you were, click the **back arrow on the left**, or press *Command+Left Arrow* (on Mac), or *Alt+Left Arrow* (on PC).

\*Providers include: doctors, nurses, physician's assistants, chaplain, therapist, social worker, nurse assistants, pharmacist, and other clinical staff







# **COLLECTION OF METHODS**





# PERSONAL NARRATIVE

Tell your stories and discover their context by seeing how they fit together into a narrative. Through this process, patients, providers, and caregivers can build connections and improve communication and understanding.

## WHEN SHOULD I USE THIS METHOD?

- To keep track of your everyday wellness.
- To reflect on and process important doctor-patient-caregiver interactions and make sense of the information received during important doctor visits in relation to your own narrative.
- To re-center yourself when you're feeling frustrated, isolated, or overwhelmed.

## WHY SHOULD I USE THIS METHOD?

- To make your voice heard, bring alive the person at center of the story.
- To provide meaning, context, and life to information or data.
- To build connection and improve communication and understanding among patient, provider, caregiver, and others.
- To reflect, process, or reframe your approach and your role, especially in difficult or confusing situations.

## BEST USED WITH:

- **Listening:** Personal stories require a patient listener.
- **Journaling:** Use daily reflections of your experiences, thoughts, and feelings to begin to build your story.
- **Expressive Arts:** Using visual forms of expression, can help you uncover deep, rich stories.
- **Storytelling With Purpose:** Use your story to shift perspectives and support widespread change.





## HOW DO I USE PERSONAL NARRATIVE AS A...

### PATIENT

**Who I Am:** Reflect on your life up to this point. Who are you? Who were you? Who do you want to be?

**Important Aspects of My Life:** Reflect on current circumstances in your life that may impact your care and healing. What’s happening in your life right now? Are their things I am doing, or relationships I have that are creating barriers to my healing?

**Reframe Your Narrative:** Create a new version of your story that will help you think through this pivotal moment in your life and put things into perspective. Ask yourself, “What opportunities lie within the challenges before me?”

**Show vs. Tell:** Give your provider and/or caregiver an audio or video recording you’ve made that captures your concern, symptoms, and history in your own words.

### CAREGIVER

**Personal Story:** You may already be close to this person, but sometimes sharing something personal about yourself and your feelings about the current experience can create even stronger bonds, or if you haven’t been close, can open up new potential in your relationship.

**Reframe Your Narrative:** This role as caregiver may not have been planned. Reflect on what this new role means to you? How might you find a way to give it meaning and purpose in your life?

**Show vs. Tell:** Consider expressing your feelings about your role or about your loved one’s illness through a visual medium—paint a picture, shoot a video, record your voice—this gives you the opportunity to reflect on what you want to say without tripping up during a face-to-face dialogue.

### PROVIDER

**Personal Story:** Relate a personal story to your patient about what they are currently experiencing, to connect with them and show them you care.

**Who I Am:** Reflect on why you decided to go into healthcare in the first place. What drew you to this work? How does that relate to your work and life, up to this point?

**Reframe Your Narrative:** Take the time to imagine a new narrative unfolding as it relates to your practice. What routines have you fallen into that may not be additive? What role do you want to play as a provider and how might you write that story?

### WORKSHEETS

*Who I Am* p114



*Reframe Your Narrative* p116



*Important Aspects...* p119





# LISTENING

Attend to someone else’s story, words, and nonverbal signals in order to acknowledge, absorb, interpret, and act on others’ stories. Listening — being attentive to and present with another’s story — lies at the heart of communication.

## WHEN SHOULD I USE THIS METHOD?

- For your everyday wellness—patient, caregiver, and provider.
- During doctor visits to gather critical information, and empathize with the experiences of others.

## WHY SHOULD I USE THIS METHOD?

- To build authentic connection by improving communication and understanding among patient, provider, caregiver, and others.
- To help others heal by “hearing them out,” witnessing their challenges, validating their perspectives, and empathizing with them.
- For providers: To understand context in order to arrive at the right diagnosis and develop appropriate care plans — saving time, resources, and costs.

## BEST USED WITH:

- **Personal Narrative:** Attending to someone who offers their story creates an opportunity for deep connection, contextual understanding, and healing.





## HOW DO I USE LISTENING AS A...

### PATIENT

**Active Listening:** As patients, we hear a lot of things being explained to us about our condition, treatment, or health status, but are we really listening? Active listening can improve relationships, understanding, and memory, all of which can lead to healthier outcomes.

**What I Heard:** During clinical visits, actively listen to the words and instructions of your provider or caregiver. Write down what you heard, as well as your thoughts and feelings after a visit to help you remember and process what was discussed.

### CAREGIVER

**Active Listening:** Conversation is a two-way street, but we aren't often taught to listen. As caregivers, we often feel the need to 'offer' counsel, but active listening can help us truly understand what is needed and how best to help.

**What I Heard:** Our loved ones are often stressed or nervous during doctor visits and their active listening may be diminished. You can help by capturing what you heard in writing, and asking clarifying questions to be sure you understand, so you are better equipped to guide and support your loved one.

**Facilitated Storytelling:** If dialogue has become difficult or strained, you can facilitate storytelling with thoughtful prompts and questions to trigger interactions between you and your loved one.

### PROVIDER

**Be present:** On average, doctors interrupt their patients within 18 seconds. Start each patient visit with a simple exercise: Sit face to face without a clipboard or computer. For the first two minutes, don't write anything down. Just be present for your patient.

**Listen for Context:** While your patient is talking, listen for clues to challenges in the patient's life that affects his or her care.

**Facilitated Storytelling:** Not all patients are comfortable initiating dialogue or sharing their personal stories. By introducing thoughtful prompts, personalizing questions, or becoming more playful in the inquiry, you in essence are giving 'permission' for the patient to explore more freely.

**What They Heard:** Check how well your patient and/or their caregiver understands what was said by asking him or her to tell you what they heard. You can use the ["What I Heard" worksheet on page 115](#) as a starting point.

**Bearing witness:** Even when you have exhausted your tools and resources and feel you have nothing more to offer your patient, you have one more tool: bearing witness to their experience in a show of compassion and solidarity.

**Workshops:** Listening attentively is a hard skill. Check out the list of resources on [page 163](#) to find training programs.

### WORKSHEETS

*What I Heard* p115



*Facilitated Storytelling* p123



*Listen for Context* p125





# CLINICAL NARRATIVE

Electronic health records (EHRs) are one of the many tools for capturing a patient's key medical information. While they are an important aspect of care, they fragment the narrative, which can lose the context of and implications for the patient's care. Placing elements of the patient's own story into data-heavy clinical tools and resources brings meaning back into the process.

## WHEN SHOULD I USE THIS METHOD?

- To ensure seamless coordination and communication for any patient visit, particularly patients with large care teams.
- To spark a dialogue among members of the care team if you get stuck regarding the best care for a patient.

## WHY SHOULD I USE THIS METHOD?

- To honor how we, as humans, naturally think in story to process and understand information.
- To provide a coherent narrative among the fragments of a patient's story.
- To support understanding of the context around the patient's illness.
- To capture the patient's perspective and voice in their electronic health record

## BEST USED WITH:

- **Personal Narrative:** Witnessing someone's story when it's offered is an opportunity for deep connection, contextual understanding, and healing.
- **Listening:** Stories require a patient listener.
- **Journaling:** Use daily reflections of your experiences, thoughts, and feelings to track your health and wellness.





### PATIENT

**Take Control of Your Record:** If your provider has an online website that gives patients access to personal health information, register and review your information. You can check out OpenNotes ([myopennotes.org](http://myopennotes.org)) to access your own medical records. Ask for printed test results or pathology reports so you can keep a copy for yourself. Make sure the information your provider has is accurate and relevant, and if you see something wrong in your record, let your provider know.

### CAREGIVER

#### **Take Control of Your Loved**

**One's Record:** If your loved one's provider has an online website that gives patients access to personal health information, with your loved one's permission, you can register and review the information. Since patients sometimes don't have the energy to track the records themselves, as caregiver, you can help by asking for printed test results or pathology reports and help manage the records. If you see something wrong in the record, discuss it with your loved one, and be sure to let the provider know.

### PROVIDER

**Add Personal Notes:** Include personal reflections and quotes from your patient's story in his or her medical chart, or when introducing them. Think of it as a way to thread together the fragments of the patient's story.

**Video and/or Audio Recordings:** Record the visit, with the patient's permission, to capture the patient story in a way that can be reviewed easily. Recordings can provide a baseline of patient symptoms and behavior, and help to share the patient's story with consulting colleagues. Also, recording instructions to share with the patient improves discharges and overall satisfaction. See the resources and apps for EHR systems listed at the end of the playbook.





# EXPRESSIVE ARTS

Have trouble telling your story with words? Try drawing or painting it. Act it out or dance it. No need to feel shy — the creative arts have been used in healthcare for decades.

## WHEN SHOULD I USE THIS METHOD?

- When dealing with trauma, discrimination, or other deep-seated issues.
- For situations in which silence is the norm, such as mental illness, stigmatized illnesses/behaviors, or marginalized groups.
- For healing body, mind, and spirit.
- For redefining one's role in light of new diagnoses or conditions.
- For building confidence and feelings of validation — especially in groups.
- For revisiting difficult conversations to understand how they could have gone better.

## BEST USED WITH:

- **Personal Narrative:** When people get to tell their stories, that alone can help them heal.
- **Journaling:** Daily reflections of your experiences, thoughts, and feelings will help you build your story.

## WHY SHOULD I USE THIS METHOD?

- To prompt discussion, reflection, and critical conversations.
  - To improve interactions and dissolve boundaries between groups (patient, caregiver, and provider).
  - To explore other perspectives, prompt new perspectives and physically work through challenges.
  - To raise awareness of hidden issues that impact care and healing, including power, privilege, bias, and assumptions.
  - To feel validated, especially in groups.
  - To find your voice, process your experience, and heal.
- 
- **Storytelling with Purpose:** Use your story to shift perspectives and support widespread change.







**PATIENT**

**DIY Artistic Methods:** Expressive arts don't require training. All that's required is an open mind and a little exploration. For instance, draw or paint your emotions. Write a song about your experience. Collage your vision of a perfect day. Try it and see what happens.

**Facilitated Expressive Arts:** Some challenges require the strength of a safe community and the guidance of a skilled facilitator. In these circumstances, try an expressive art workshops aimed at your particular situation, such as those listed in this [worksheet](#).

**CAREGIVER**

**DIY Artistic Methods:** No need to be intimidated by the term 'art'. Art is individual, and in the eyes of the beholder. You can try your hand at expressing your own feelings about your role, or offer to draw, paint or write a song together with your loved one, for fun and for healing!

**Facilitated Expressive Arts:** Perhaps you see value in the expressive arts, but just are not comfortable exploring or assisting your loved one in the activity. There are plenty of facilitated expressive arts workshops to guide you. You can check some of them out in [worksheet](#).

**PROVIDER**

**DIY Artistic Methods:** The difference between art and science isn't as big as some may think. Science is about exploration and discovery and so is art. They both require creative thinking. No formal training is needed to explore, so try picking up a paint brush or a musical instrument—or just put pen to paper and write a poem—and see if you discover something new about yourself, your feelings about your role as a provider, or even about your patients.

**Facilitated Expressive Arts:** If you have tried expressive arts and see the value, but feel just too 'left-brained' to do it on your own, don't give up! There are professionals who are trained to draw it out of you (pun intended). This can work both for you personally as a provider, or perhaps suggested to your patients. See some recommendations in this [worksheet](#) to get you started.

**WORKSHEETS**

*DIY Expressive Arts* p117



*Facilitated Expressive Arts* p118





# JOURNALING

This method couldn't be simpler — just record your thoughts regularly (preferably each day).

Write about what's happening with you, what you've seen and experienced, and your reflections.

## WHEN SHOULD I USE THIS METHOD?

- For expression, clarification, and catharsis of day-to-day challenges and experiences.
- For sharing the progress of a loved one, especially in situations such as sudden illness, mental illness, or terminal illness.
- For a therapeutic way to process trauma and to reflect on psychiatric or psychological sessions.
- For building a habit of self-reflection and self-awareness.

## WHY SHOULD I USE THIS METHOD?

- To track daily fluctuations in mood and symptoms.
- To revisit conversations and evaluate their outcomes.
- To express privately thoughts, encounters, exchanges, and emotions, including those you may not want to talk to anyone about.
- To cope with traumatic events or painful situations.
- To process your experiences.
- To improve your decision-making skills.
- To bring some relief for many symptoms, including anxiety, depression, or general tension.

## BEST USED WITH:

- **Personal Narrative:** Daily writing can help build a larger personal story.





## HOW DO I USE JOURNALING AS A...

### PATIENT

**Daily Reflection:** Carve out time each day to write down thoughts and feelings. Patients should especially write reflections after important health news is delivered, difficult treatments are undertaken or upsetting interaction with loved ones have occurred.

**Blogging:** Writing about your health experiences or illness on a public-facing blog can help you connect with others facing the same issues. You'll gain information, create a community, and relieve stress and isolation. You may start blogging to get help, but as you share and connect, you'll shift from one who is helped to one who helps — and in the process regain meaning and purpose in your own life.

### CAREGIVER

**Daily Reflection:** Keeping track of your daily experiences as a caregiver can both help you reflect and come to terms with your role. It can also serve as a possible resource for sharing your feelings with your loved one when/if you both decide it is right. Daily reflections can be particularly helpful after sentinel events, such as just after diagnosis or difficult treatments.

**Blogging:** There are robust caregiver networks out there, and tapping into them can provide terrific support. Writing about your experiences as a caregiver can not only help you confront your own stresses and challenges, but may also help other caregivers find comfort in knowing they are not alone.

### PROVIDER

**Daily Reflection or Witnessing:** Writing about sentinel events and other difficult experiences allows you to process and cope with unexpressed feelings. While this is used mostly in clinical supervision and teaching, it can provide ongoing stress relief and catharsis.

**Blogging:** Among the reasons that doctors blog: Archiving information and scientific advancement, educating others, marketing themselves, reflecting on frustrations with the healthcare system, achieving catharsis. Make sure to stay current on the risks of and best practices for physician blogging.<sup>2</sup>

**Health Journaling:** Have your patients track key aspects of their health and relevant aspects of their life outside healthcare settings, and share their writing with you. This can create a non-intrusive connection between you and your patients, as well as highlight patterns, habits, and behaviors that affect their health.

### WORKSHEETS

*Daily Reflection* p124





## PEER-TO-PEER SHARING

Join or create a community whose members share health challenges. You can connect to peers either online or offline to learn from and share stories with one another.

### WHEN SHOULD I USE THIS METHOD?

- When you feel isolated.
- For validating and working through feelings of frustration and confusion with others.
- For exploring different perspectives.
- For researching real-world examples of what to expect with specific illnesses.

### WHY SHOULD I USE THIS METHOD?

- To share experiences and feel less isolated.
- To move confidently toward mentoring those newly diagnosed.
- To foster resilience and gain an understanding of what to expect with specific health conditions.

### BEST USED WITH:

- **Personal Narrative:** Sharing your story with others is an opportunity for deep connection, contextual understanding, and healing.
- **Listening:** Stories require a patient listener.





### PATIENT

**Reach Out:** Many people overlook this simple gesture. This could be asking for help for yourself, or offering help to those in need. When we feel vulnerable it can be difficult to open up, but our loved ones sometimes feel helpless, and so many will appreciate knowing how they can help—even if ‘helping’ means just listening.

**Support Groups:** Use support groups to share your story with others who have similar experiences—particularly for trauma, mental illness, and marginalized or stigmatized groups. It creates a network of support and better coping strategies for dealing with challenges.

**Online communities:** There are a number of online communities and databases of patient, clinician, and caregiver stories. By connecting to those with similar conditions or challenges, you can create a community of support for yourself.

### CAREGIVER

**Reach Out:** When caring for others, it is very easy to forget that we need care too. Asking others for help, especially from those we are caring for, can feel backwards or just awkward. We care better when we feel better. Remember that those we are caring for love us too, and want to know how they can help.

**Support Groups:** Group support isn’t just for patients. Caregivers are typically taking on a role that is foreign and overwhelming. By connecting with formal groups on the topic, you are able to learn from others and share your wisdom as well.

**Online communities:** Caregivers often have very full schedules, having taken on this role in addition to their already busy lives. If attending support groups or facilitated sessions on expressive arts simply does not fit into your current regimen, online communities are a great time-saving way to jump in and out of conversations and information sharing during those rare moments of respite.

### PROVIDER

**Reach Out:** Providers spend a lot of time helping others, which can be both rewarding and draining. It is important to take time to reflect on where you could use some help too. It will give you the strength and motivation to continue to do your good work. In the process of sharing with your peers, you might just be, yet again, helping someone else.

**Online communities:** More and more online communities for providers are emerging, and if you can’t find one you like, perhaps consider starting one! Connecting with other providers online is a terrific time-saving way to stay connected, share challenges, get inspired, or inspire others.





## INDIVIDUALIZED LEARNING

Gather information from the stories and experience of others through books, articles, videos, films, and online searches. This looks like peer-to-peer sharing, but in this case it's one-sided, rather than a conversation.

### WHEN SHOULD I USE THIS METHOD?

- For exploring different perspectives.
- For gaining an understanding of what to expect with specific health conditions in order to best manage care.

### WHY SHOULD I USE THIS METHOD?

- To learn about other's experiences without interacting with anyone or sharing your own story.
- To foster resilience and gain an understanding of what to expect with specific health conditions.
- To reduce isolation by providing perspective and understanding you are not alone in this experience — that others have traveled this road.

### BEST USED WITH:

- **Peer-to-Peer Sharing:** Connecting with others can add more depth and context to what you're learning.





## HOW DO I USE INDIVIDUALIZED LEARNING AS A...

### PATIENT

**Information Gathering:** Search books, articles, videos, films, and online resources to find information that you relate to, even if it's not about the same condition or challenge. Learning from such resources can give us strength, help us understand, or inspire thoughts about how best to move forward. It's important to remember that it isn't just about curing an illness or condition, it's about healing emotionally, and there can be very different resources for each.

### CAREGIVER

**Information Gathering:** Learning comes in many forms. As caregivers, we may think of our learning needs as those solely focused on understanding our loved ones condition or treatment options. Exploring new healing methods, reading up on coping strategies, getting inspired by a heroes journey from tragedy to triumph can not only be cathartic for us individually, but can also serve to create stimulating or healing dialogue between you and your loved one.

### PROVIDER

**Information Gathering:** Searching for inspiration and information to help us forward our practice has never been easier. There is a plethora of healthcare publications we can subscribe to, but that is not the only source of information and inspiration. Sometimes, looking beyond our own field of work can inspire new thoughts, ideas or opportunities to improve our practice. Consider spending time reading up on innovations in other fields such as education, the arts or retail. Exploring ideas in parallel worlds might inspire new thinking, or perhaps even just give you some fodder for connecting with your patients! Not a lot of time? Try listening to new radio stations or podcasts on the way to and from work.

### WORKSHEETS

*Health Information Organizer* p120 





## STORYTELLING WITH PURPOSE

Have you had a traumatic, frustrating, or confusing experience that others might experience too? Use your story for a purpose: To spark empathy and to explain, justify, or clarify misperceptions. Your story has the power to change people and institutions through public art, presentations to community leaders, or even a simple letter.

### WHEN SHOULD I USE THIS METHOD?

- When you are preparing to share your story with your care team and others.
- For cataloging good or bad experiences with the healthcare system.
- For activism that could inform and persuade others, and perhaps get new policies created or legislation passed.

### WHY SHOULD I USE THIS METHOD?

- To develop leadership skills.
- To make sure your voice is heard.
- To raise awareness of important healthcare issues and challenges that you and others must go through.

### BEST USED WITH:

- **Personal Narrative:** Sharing your story with others is an opportunity for deep connection, contextual understanding, and healing.
- **Expressive Arts:** Visual forms of expression can help you uncover deep, rich stories.
- **Individualized Learning:** Build a foundation of information and stories from others to support your learning.







## HOW DO I USE STORYTELLING WITH PURPOSE AS A...

### PATIENT

**Tell Your Story Effectively:** We all know how fast our doctor's appointments go — and that's the healthcare system's fault, not the doctor's. We barely have to time to greet the doctor, much less share what's going on with us. Use purposeful storytelling to make the most of your time with your care team.

**Send a Letter:** If you can't resolve a problem with your provider in face-to-face, you can write a letter. Send it directly to him or her, and/or to the hospital where you were treated. If it is really important to your health or treatment plan, and you are not getting a response after repeated inquiries, you can consider sending a copy to your local Board of Health.

**Create Public Art:** Art can bring out feelings, get people thinking, and explore different perspectives. The effect is even stronger for public art. Flash mobs, performance art, murals, and more can raise awareness of challenges you and others face. A local public art program may help you find ways that you can create public art.

**Present Your Story:** Present your story publicly at a conference or speaker summit. You can also become a patient representative to the US Food and Drug Administration (FDA) or other government agencies, to make sure the patient voice is heard during policy discussions.

### CAREGIVER

**Tell Your Story Effectively:** Your loved one is often shuffled in and out of appointments, and the focus for both them and the provider is likely on the facts, the data and the next steps. You can help by taking the time to help them pause, reflect, and share. It will help provide critical context and ultimately lead to both a more pleasant experience and a more appropriate care or treatment plan.

**Send a Letter:** Sometimes, despite our best efforts to resolve all issues face-to-face, we either run out of time with our provider, or simply forget under all of the rushing or stress. Encourage your loved one not to let it go if it was important to them. Sending a letter can sometimes lead to more thoughtful reflection—both in the question and in the answer.

**Create Public Art:** Occasionally, our advocacy for an important issue related our loved one can fall on deaf ears, due to an overwhelmed healthcare system. Consider making a thoughtful, peaceful statement that can't be ignored — because of its powerful messaging and its beauty. Use your talents, or that of others, to produce a mural, a musical piece, an internet video that can go viral, or some other artful expression that speaks to you and others facing similar challenges.

**Present Your Story:** More and more opportunities for caregivers to formally share their stories are popping up. Check out conferences for caregivers online and see about sharing your unique experience, point of view, or even ideas for how to improve the caregiving experience!

### PROVIDER

**Presentations:** Present your experience publicly at a conference or speaker summit. Use the platform that grand rounds offers to share stories that raise awareness of important issues.

**Raise Awareness:** If your organization has a platform for sharing ideas, consider sharing your stories, and those of your colleagues, in new and unique ways—create a 'story wall', organize a healthcare theatre group, run an art or photo contest around a specific topic—to raise awareness internally, and with leadership. By adding an element of fun, whimsy, or humor you are better able to speak to some truths and realities in healthcare without generating defensiveness or creating turmoil.

### WORKSHEETS

*Reframe Your Narrative* p116 



*I am a*

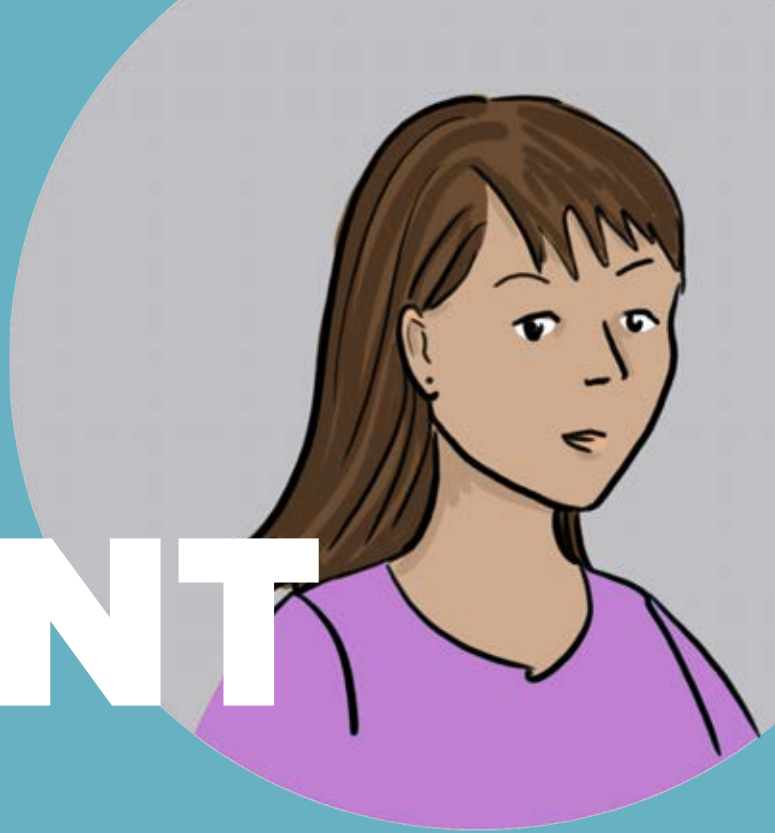
# PATIENT

I FEEL FRUSTRATED WITH THE HEALTHCARE SYSTEM.

MY DIAGNOSIS HAS CHANGED EVERYTHING.

I FEEL ISOLATED.

I FEEL STRESSED AND HELPLESS.



*Although we play different roles in our lives — daughter, son, mother, father, husband, wife, colleague, boss — in healthcare we are all patients, whether we are healthy or sick.*

As patients, we can easily lose touch with who we are outside the hospital or the doctor's office. Getting lost in diagnoses and data affects our decision-making abilities. We can become disconnected from those we need most — family, friends, loved ones. Worse, we may feel unheard in hurried visits with our provider and care team.

Narrative helps us when we are well, but it's most powerful when we are unwell and feeling alone, isolated, overwhelmed, misunderstood, or defeated. At times when “the top 10 things on your ‘to do’ list are all the same: Your health.”

This playbook is meant to help those of us in the patient role work through our feelings and our decision-making about diagnoses or difficult news. The methods here will help us process our experiences, reframe our points of view, and share our stories. With these methods we can connect with others who feel as we do and build our resilience in the face of health challenges. Finally, narrative can help us shine light on important issues that may require big changes in healthcare.





## NARRATIVE for EVERYDAY WELLNESS

*How to build a foundation of narrative into our everyday lives.*

**PERSONAL NARRATIVE** (pg 18): Our stories help build connections by improving communication and enhancing understanding. They can also help us reflect, process, or redefine situations and roles.

### ***What's your story?***

Use the **worksheets** on page 113 to capture thoughts and feelings about your health, as well as important things you want to bring up during appointments.



---

**JOURNALING** (pg 26): Daily journaling is a great way to review each day. These don't have to be long or complex reflections. Even quickly jotting down thoughts a few times a week can help you track your physical, emotional, social, and spiritual well-being.

**Studies show** that writing can bring major health benefits, from fewer doctor visits to improved memory.<sup>3,4</sup>



**LISTENING** (pg 20): Conversation is a two-way street, but we aren't often taught to listen well. Active listening — hearing not only the words, but more importantly, understanding the message — can improve our relationships, understanding, and memory, all of which can lead to better health.

**When “actively listening”**, a simple but effective trick is reflecting back what you're hearing and understanding: “What I'm hearing is...” or “Sounds like you are saying...”

---

**STORYTELLING WITH PURPOSE** (pg 32): Doctor appointments are often fast and brief — and that's not the doctor's fault, but thanks to our healthcare system. Effective storytelling can help us make the most of the time we have with our care team.

**Learn how** to communicate important points about yourself clearly and effectively by using the **worksheet** on page 121.



*Learn how others have built narrative into their daily practice in our Story Bank (pg 127).*



*Hear the provider's narrative:* When meeting and deciding to work with a new provider, ask questions that allow the provider to talk about his or her personal passions and commitments. “Tell me about why you chose [specialty].” “What do you love most about being a [profession]?” “Where, when, and how do you discover meaning in your work?”



Paul Kalanthy, a Stanford neurosurgeon, was diagnosed with stage IV lung cancer at the age of 36. In navigating his uncertain future, the provider-turned-patient found comfort in seven words from writer Samuel Beckett, “I can’t go on. I’ll go on.” Those words gave him the strength to face his own mortality. They repeated in his head as he woke up each day: “I can’t go on.” And they repeated in his head as he continued his life — in his scrubs, heading to the operating room: “I’ll go on.” Paul Kalanthy passed away on March 9, 2015 — less than two years after his diagnosis.

*As reported in the 2014 New York Times article,  
“How long have I got left?” by Paul Kalanthy*



***I'm frustrated  
with the  
healthcare  
system.***



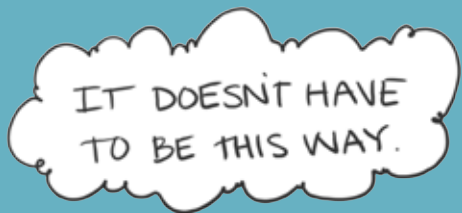




## ***“After I finished treatment, I kept having this recurring daydream.***

I was floating over my own funeral, listening to people talk about how I'd lived so long considering all the cancer in my liver, what a fighter I was; what a testament it was to how much I loved my kids. I remember wanting to scream: 'No! I didn't have to die! I could have lived! I didn't have dozens of tumors in my liver, only one!'

When you're diagnosed, you feel like the healthcare system is trying to find a way to get you on the moving walkway, progressing toward treatment. When you try to take time to learn about all the options, and make a decision based on your own values, you're off the moving walkway, not complying with the plan that's been presented, not checking a box. Keeping track of you, as you take



the time YOU need, requires them to adapt to your timing, your process. And that's not efficient or profitable for the system which wants, above all, for you to get in the system, on the walkway.

I was blessed with survival, and with the chance to create something that gives meaning to an experience that changed my life, to seek to ease the burden for others. At the Center for Patient Partnerships, we train future doctors, nurses, pharmacists, lawyers – anyone who interacts with patients – to decrease the burden of suffering, not to add to it by how they approach people who are sick and frightened. They must insist on humanity, theirs and ours. My work is a profound gift.”

*Meg Gaines, Associate Dean at University of Wisconsin Law School, on the impetus for developing the Center for Patient Partnerships*



# TRY OUT...

## PERSONAL NARRATIVE

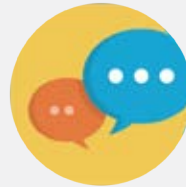
Sometimes we need space and distance to put things into perspective. Make time to reflect on your health and how it affects your past, present, and future stories. If you feel comfortable doing so, share this with your doctors so they better understand your perspective.



*Writing about traumatic events not only helps you process them, but may lead to better health.<sup>5</sup> Use the prompt on page 124 help you explore your feelings.*

## PEER-TO-PEER SHARING

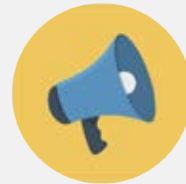
Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others — either face-to-face or online — to share your story and listen to theirs.



*For personal topics that are difficult to share, check out [PatientsLikeMe.com](https://www.patientslikeme.com), [healthtalk.org](https://www.healthtalk.org), [inspire.com](https://www.inspire.com), or [wegohealth.com](https://www.wegohealth.com) to connect as an anonymous user with engaged and supportive patient communities.*

## STORYTELLING WITH PURPOSE

Have you experienced something confusing, frustrating, or traumatic that others might also be experiencing? Your story can help make change happen.



*See how others have used their stories to raise awareness on important healthcare issues in our Story Bank on page 148.*



HAVING TROUBLE WITH EXPRESSING YOURSELF WITH WORDS?

*Try using **Expressive Arts** to find your voice (pg 117).*



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### **ROLE PLAYING**

can be a great way to physically work through challenges, gain new perspectives about your situation, and connect with others, all at the same time. Check out the Facilitated Expressive Arts reference sheet on page 118 for different ways theater can help.



***My diagnosis  
has changed  
everything.***

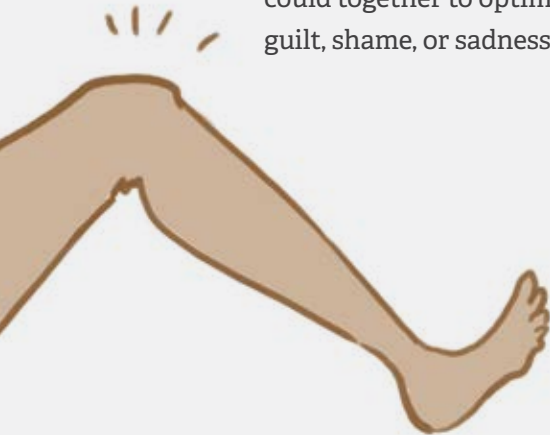




***“My orthopedist delivered the news that I needed knee replacements with his head hung low.***

‘I hate to tell you this, because you’re so young,’ he said. My response was to reframe the issue for him. ‘I was only 13 when I was diagnosed with my first chronic condition, only 24 with my second illness, so if I am only 44 for this, that is okay.’ With that, we both were able to move ahead to make the best decisions we could together to optimize our knee replacement experience, unencumbered by guilt, shame, or sadness.”

*Donna Cryer, President & CEO of  
the Global Liver Institute*



## TRY OUT...

### PERSONAL NARRATIVE

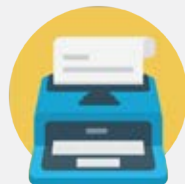
Sometimes we need space and distance to put things into perspective. Make time to reflect on your health and how it affects your past, present, and future stories. If you feel comfortable doing so, share this with your doctors so they better understand your perspective.



*Reframing your experience and creating a new version of your story can help put things into perspective. You can use the Reframe your Narrative worksheet page 116 to think through the changes in your life.*

### JOURNALING

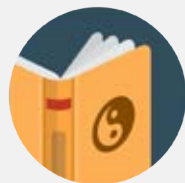
Daily journaling is a great way to process each day. These don't have to be long or complex reflections. Even quickly jotting down thoughts a few times a week can help you track your physical, emotional, social, and spiritual well-being.



*Starting your own blog — illness-related or not — provides relief from pressure, raises awareness of your condition, and helps you create your own supportive community. CaringBridge.org has great resources to help you get started.*

### INDIVIDUALIZED LEARNING

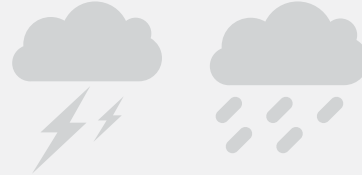
With so much being published these days on different conditions and illnesses, you can learn how others have managed experiences like yours. Look for newspaper and magazine articles and movies about health challenges, as well as books (memoirs by people with illnesses are especially good).



*To avoid information overload, see the tips on page 120 for keeping your care, treatment, and yourself organized.*



A **terminal diagnosis** triggers  
a **hailstorm of emotions**.  
As you navigate the storm,



*CONSIDER RECORDING YOUR LIFE  
STORY FOR YOUR LOVED ONES.*



Include memories, advice, or even instructions,  
to pass on your full story and not the bits and  
pieces found in photos and memories.



They say laughter is the best medicine,  
and it's true. **REALLY.**

Humor therapy is promoted by the American Cancer Society  
as a complement to traditional treatment.<sup>6</sup> Do an online  
search for “humor” and “illness” and see what comes up.





***I feel isolated,  
alone, and  
disconnected  
from others.***





## ***“It took a child to help me understand the power of connection when one has a chronic illness.***

My son, Nick, was diagnosed with a rare form of cancer when he was 14 years old in 2000. We quickly became overwhelmed with the complexity of managing a life-limiting illness — hospital admissions and readmissions, surgeries, chemotherapy and radiation schedules, pain that could not be adequately managed even with the most potent analgesics. After one particularly difficult day, Nick turned to me and said “I just want to be a kid again” — in that instant I realized that through the diligent management of his disease we had all lost sight of the person, Nick, the teenager.

We found a way, in the early days of online chat, for Nick to be connected to his friends back home, through a borrowed laptop computer and a dial-up connection in his hospital room — he

became a kid again, part of the world, sharing stories, homework, jokes, gossip, and typical teenage angst. Tragically, my son did not survive his illness, but he left me with profound gratitude for the lesson he taught me — we are much more than our diagnosis and through connecting with others and by sharing our stories, we can reclaim a bit of our citizenship in the world of the well.”

*Pamela Ressler, Founder of Stress Resources & Faculty of Pain Research, Education & Policy Program at Tufts University School of Medicine*



## TRY OUT...

### PERSONAL NARRATIVE

Sometimes we need space and distance to put things into perspective. Make time to reflect on your health and how it affects your past, present, and future stories. If you feel comfortable doing so, share this with your doctors so they better understand your perspective.



*Use the worksheet on page 114 to think about big important questions and reconnect you to who YOU are.*

### EXPRESSIVE ARTS

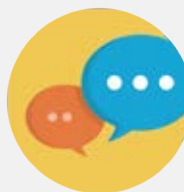
Words don't always come easily. You may find it easier to draw, paint, dance, or write a poem or a play about how you feel. In an arts group, you can express yourself in a supportive atmosphere.



*For a listing of local writing and art workshops near you, check out the resources on page 163.*

### PEER-TO-PEER SHARING

Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others — either face-to-face or online — to share your story and listen to theirs.



*Support groups help you connect with others who are going through similar experiences in a safe and caring environment. Check out the resources on page 164 to find a group that's right for you.*



**Learn how others have overcome**  
FEELINGS OF ISOLATION  
**through story in our Story Bank pg 127**



---

## FIND FILMS OR STORIES

about people struggling with health challenges like yours, to find out how others have dealt with similar issues. These can be cathartic, and can help you decide how to move forward.



***I feel stressed  
and hopeless  
about my  
situation.***







## ***“Today a year ago my life was turned upside down***

Today a year ago I got the bad news  
Today a year ago I thought I was gonna die within a few years  
Today a year ago my mind went into shock  
Today, I actually had a lot of fun  
Today I celebrated my first-year anniversary  
Today the world looks completely different  
Today I am me again  
Today I actually cried tears of laughter and not of sadness

Yes, my life has been affected by HIV and if not treated, it's life-threatening. But I had time to get over it. My doctors have been taking fantastic care of me. I started my meds a few months ago even though I didn't need to yet, but I wanted to preserve my brains and guts. I made a lot of new friends and some of them have become really close. I have been on stage, which I never thought I would. I even had sex again — I felt like a virgin but I did it (-:-). I went through ups and downs as has everyone, but overall I have to say I made it another year and it was definitely not my worst and also not my last. So people, watch out — here I come again, better than ever.”

*Reflections from HIV-positive woman participating in  
The Medea Project: HIV Circle, an expressive theater intervention  
Copyrighted by Cultural Odyssey and Rhodessa Jones 2010*





## TRY OUT...

### PERSONAL NARRATIVE

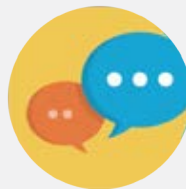
Sometimes we need space and distance to put things into perspective. Make time to reflect on your health and how it affects your past, present, and future stories. If you feel comfortable doing so, share this with your doctors so they better understand your perspective.



*Reframing your experience can help put things into perspective. Use the [Reframe Your Narrative worksheet](#) on page 116 to consider a new, empowered narrative for yourself.*

### PEER-TO-PEER SHARING

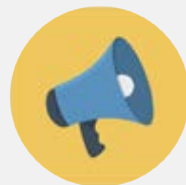
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*Support groups help you connect with others who are going through similar experiences, in a safe and caring environment. Check out the [resources](#) on page 164 to find a group that's right for you.*

### STORYTELLING WITH PURPOSE

Have you experienced something confusing, frustrating, or perhaps traumatic that others might be experiencing? Your story can help make change happen.



*See how others have used their stories to raise awareness on important healthcare issues in our [Story Bank](#) on page 148.*





Having trouble expressing yourself with words?

***Try using Expressive Arts to find your voice (pg 24).***

---

### **IF YOU FEEL TRULY HOPELESS —**

enough that you are considering taking your own or someone else's life —  
you can get immediate help by calling a suicide hotline.

**You can reach the National Suicide Prevention Lifeline at 800-273-TALK.**





*I am a*

# CAREGIVER

I FEEL FRUSTRATED WITH THE HEALTHCARE SYSTEM.

MY LOVED ONE'S DIAGNOSIS HAS CHANGED EVERYTHING.

I FEEL ISOLATED.

I FEEL COMPLETELY OVERWHELMED.



*Your loved one needs your help. You didn't ask for this responsibility, but "no" wasn't even on the table. So you work your way through this world of caretaking as best you can, often with little support from others. Our hats are off to you, whether you're still juggling a job or have devoted your full-time efforts to your loved one's care—whether you're hands-on day-to-day, or organizing a team of caregivers.*

Your plate is full with information, decisions, financials, emotions, roles, responsibilities, and more. Your loved one may depend on you, yet you both still need your independence. You want to stay engaged and continue to build good memories, but it's hard when you're spending your time documenting his or her daily habits. Guilt, frustration, confusion, and even devastation are common. But things can get easier.

This playbook can help you harness the power of narrative to help yourself. Narrative can unearth previously hidden insights about your loved one. It can help connect information and data to a meaningful story that makes sense. It can clarify the decisions you've been struggling with. It can provide respite from an overwhelming and difficult role, because you can't care for others if you don't care for yourself. And it can provide the space to grieve and mend broken hearts.





## NARRATIVE for EVERYDAY WELLNESS

*How to build a foundation of narrative into our everyday lives.*

**PERSONAL NARRATIVE** (pg 18): Our stories help build connections by improving communication and enhancing understanding. They can also provide a way to reflect, process, or redefine situations and roles.

### ***What's your story?***

Use the **worksheets** on pages 113 to capture thoughts and feelings about your loved one's health, as well as important points you want to make during appointments.



**JOURNALING** (pg 26): Daily journaling is a great way to review each day. The entries don't have to be long or complex reflections. Even quickly jotting down thoughts a few times a week can help you track your physical, emotional, social, and spiritual well-being.

**Studies show** that writing can have health benefits for caregivers — from lowering stress to making difficult emotions more manageable.<sup>7,8</sup>



**LISTENING** (pg 20): Conversation is a two-way street, but we aren't often taught to listen well. Active listening — hearing not only the words, but more importantly, understanding the message — can improve our relationships, understanding, and memory, all of which can lead to healthier outcomes.

**When “actively listening,”** a simple but effective trick is reflecting back what you're hearing and understanding: “What I'm hearing is...” or “Sounds like you are saying...”

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**STORYTELLING WITH PURPOSE** (pg 32): Doctor appointments are often fast and brief, thanks to our healthcare system. Effective storytelling can help us make the most of the time we have with our loved one's care team.

**Learn how** to communicate important points about your loved one clearly and effectively by using the **worksheet** on page 121.



*Learn how others have built narrative into their daily practice in our Story Bank on page 127.*



*Hear the provider's narrative:* When meeting and making a decision to work with a new provider, ask questions that invite the provider to talk about his or her personal passions and commitments. “Tell me about why you chose [specialty].” “What do you love most about being a [profession]?” “Where, when, and how do you discover meaning in your work?”





***“As my mom  
deteriorated from Alzheimer’s,***

she was less and less participatory, so the challenge was to remember I was there to help her and at the same time allow the providers space to do their jobs. One very exceptional nurse pointed out that if I was spending my time documenting her daily habits, then how could I be engaging with her as her son?”

*Bill Hill, Founder of Experience Design, Inc.*

***I'm frustrated  
with the  
healthcare  
system.***





*PERHAPS...*

*I don't trust the medical system.*

*I feel my loved one or I experienced discrimination.*

*I feel misunderstood.*

*Our treatment plan isn't working.*

*We are not being listened to.*

*I don't have the right resources to give good care.*

*My loved one's care isn't covered.*





## ***“After suffering and months of pain,***

a young husband and father is diagnosed with metastatic kidney cancer. His wife and family struggle to get him appropriate care during 11 weeks of continuous hospitalization at five different facilities. Frustrated and heartbroken, they turn to art as a way to make sure no one else has to go through what they did. The husband died, but the wife begins a series of public murals about their experience, and founds an advocacy movement by painting patient stories on the backs of business suit jackets. She calls it The Walking Gallery, where stories became the gateway to talking about patient rights. For her: “I paint because it’s the best way I know to make a difference. I will paint our sorrow on a wall for all to see. It’s hard to look away. It makes you think. It makes you question.”

*Inspired by the story of  
Regina Holliday and her Walking Gallery*



## TRY OUT...

### PERSONAL NARRATIVE

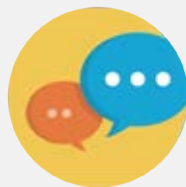
Sometimes we need a bit of space and distance to put things into context. Make time to reflect on your loved one's health and the impact on your past, present, and future story. If you feel comfortable doing so, share this with your loved one and his or her doctors so they better understand your perspective.



*Writing about traumatic events not only helps you process them, but may lead to better health.<sup>9</sup> Use the prompt on page 124 help you explore your feelings.*

### PEER-TO-PEER SHARING

Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others — either face-to-face or online — to share your story and listen to theirs.



*For topics specific to providing care for your loved one, check out [CaringBridge.org](http://CaringBridge.org), [CareGiving.com](http://CareGiving.com), [Caringroad.com](http://Caringroad.com), or [Inspire.com](http://Inspire.com) to connect to engaged and supportive caregiver communities.*

### STORYTELLING WITH PURPOSE

Have you experienced confusing, frustrating, or perhaps traumatic events that others might also be experiencing? Your story can help make sure others don't suffer the same way.



*See how others have used their stories to raise awareness on important caregiving issues in our [Story Bank](#) on page 148.*





USE *emotion* TO FIND YOUR MESSAGE —  
*THEY ARE OUR GUIDES AND SIGNPOSTS FOR WHAT DOES AND NOT WORK FOR US.*  
LISTEN TO YOUR EMOTIONS AS YOU WRITE AND SHARE.  
VIEW THEM AS YOUR ALLIES.

---



*can be a great way to physically work through challenges,  
gain new perspectives about your situation,  
and connect with others, all at the same time.*

Check out the [Facilitated Expressive Arts reference sheet on page 118](#)  
for different ways theater can help.



***My loved one's  
diagnosis  
has changed  
everything.***



*PERHAPS...*

*We don't know where to start.*

*I have no idea what to expect.*

*I need more information.*

*I need hope — something positive to focus on.*

*We should get a second opinion.*

*I feel like I'm losing myself in my caregiving role.*

*I'm worried about caring for my loved one.*

*My support system is getting burnt out.*

*We are simply trying to make the best decisions together.*





It's hard to separate the patient from the person, and that's not fair to you, but sometimes, I forget that your spirit is untouched... it's just the body that's having issues. But it's the body that might not be with me in the end.

To some degree, I'm mourning the loss of you prematurely, but once I'm past this, I'll be able to appreciate the indeterminate amount of time we have left.

And yes, you warned me of all of this. I didn't heed the warnings. I guess faith gets in the way sometimes.

In some way, I need to overcome the loss of potential — of potential in the future, trips, thoughts — and then, I'll be okay. Not that we still don't have a ton of potential left.

It's a lot to chew on at the moment... please don't hold that against me."

*Letter from a caregiver to his loved one, after she was diagnosed with a life-altering condition*



## TRY OUT...

### PERSONAL NARRATIVE

Sometimes we need a bit of space and distance to put things into context. Make time to reflect on your loved one's health and the impact on your past, present, and future story. If you feel comfortable doing so, share this with your loved one and his/her doctors so they better understand your perspective.



*Reframing your experience and creating a new version of your story can help put things into perspective. You can use the Reframe your Narrative worksheet on page 116 to think through this pivotal moment in your life.*

### LISTENING

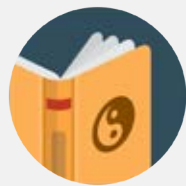
It's likely you'll have difficult conversations with your loved one, their team, and others. Take time to cultivate your active listening skills so you can listen, empathize, and hear out your loved one.



*If you're having trouble understanding what your loved one is thinking or experiencing, use the Facilitated Storytelling prompts on page 123 to help them share their story.*

### INDIVIDUALIZED LEARNING

With so much being published these days on different conditions and illnesses, you can learn how others have managed experiences like yours. Look for newspaper and magazine articles and movies about health challenges, as well as books (memoirs by people with illnesses are especially good).



*To avoid information overload, see the tips on page 120 for keeping your care, treatment, and yourself organized.*







CONSIDER STARTING A **BLOG**  
*to share updates about your loved one  
with family members and friends.*

CARINGBRIDGE.ORG HAS GREAT  
RESOURCES TO HELP YOU GET STARTED.

---



WHEN YOU NEED TO **ADVOCATE** FOR YOUR LOVED ONE,  
*TRY SHOWING RATHER THAN TELLING.*

USE PICTURES AND AUDIO OR VIDEO RECORDINGS THAT CAPTURE YOUR  
CONCERNS, SYMPTOMS, OR EXPERIENCES TO SHARE WITH THE CARE TEAM.

**KEEP IT SHORT BUT *sweet.***



***I feel isolated,  
alone, and  
disconnected  
from others.***



*PERHAPS...*

*I feel like I can't trust anyone.*

*I'm lonely.*

*I'm sad.*

*I'm scared.*

*I'm ashamed of my health issues.*

*I feel discarded by others.*

*I've exhausted my support system.*

*I feel like I've got no one to help me.*



## ***Writing helps me overcome isolation.***

A caregiver in one of my groups said she had to do her mountain climbing and that's what she did to overcome isolation. She got someone to take care of her husband and went mountain climbing. Do what you love: if you're a dancer, dance. If you're a singer, sing. Everybody can sing. That's one thing I don't do without Abe. I think I should sing more. My mother used to sing all the time. Maybe I'll start singing. I'll put some Joan Baez on."

*From a 2013 Alzheimers.net interview with Esther Altshul Helfgott,  
author of Dear Alzheimer's: A Caregiver's Diary and Poems*



## TRY OUT...

### PERSONAL NARRATIVE

Sometimes we need a bit of space and distance to put things into context. Make time to reflect on your loved one's health and the impact on your past, present, and future story. If you feel comfortable doing so, share this with your loved one and his or her doctors so they better understand your perspective.



*Use the worksheet on page 114 to think about big important questions and reconnect you to who YOU are.*

### EXPRESSIVE ARTS

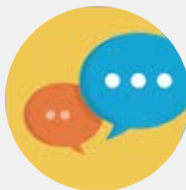
Sometimes it's hard to put our feelings into words. By using expressive arts — such as drawing, painting, dance, poetry, and theater — in a group setting, you can process what you are experiencing in a supportive atmosphere.



*For listing of local writing and art workshops near you, check out the resources on page 163.*

### PEER-TO-PEER SHARING

Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others — either face-to-face or online — to share your story and listen to theirs.



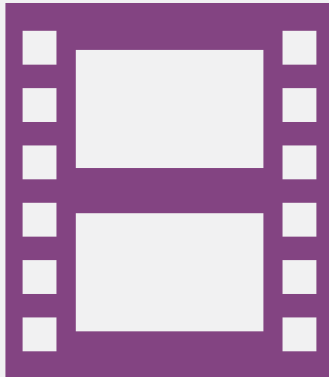
*Support groups provide a safe and caring environment in which you can connect with others going through similar experiences. Check out the resources on page 164 to find a group that's right for you.*





LEARN HOW OTHERS HAVE OVERCOME  
FEELINGS OF ISOLATION  
BY USING STORY & NARRATIVE ON PAGE 144.

---



FIND **FILMS**  
OR *stories*

***about similar health challenges***  
to discover how others have  
***dealt with similar experiences.***

These can help us better understand  
***how we feel and how to proceed.***



***I feel completely  
overwhelmed  
and burnt out.***



*PERHAPS...*

*My loved one isn't getting better.*

*I feel defeated.*

*I feel powerless over what's going on.*

*I'm dealing with dark moments.*

*I feel lost.*

*I feel scared.*

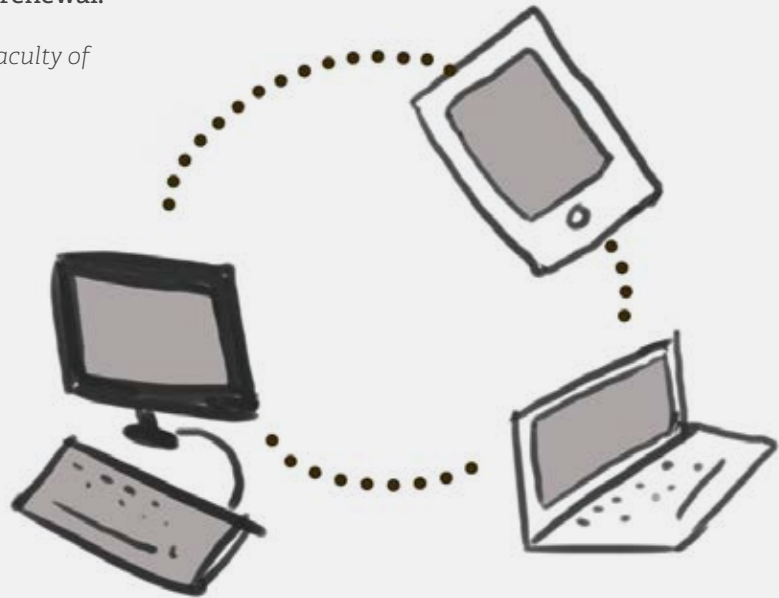
*I feel confused.*



***“While the stories of caregivers are intertwined with those for whom they care,***

*they have their own stories as well. Peer-to-peer communities serve to connect and share experiences of caregiving. Digital technology platforms allow caregivers to create a space in which to reflect and find some respite and renewal.”*

*Pamela Ressler, Founder of Stress Resources & Faculty of Pain Research, Education & Policy Program at Tufts University School of Medicine*



## TRY OUT...

### PERSONAL NARRATIVE

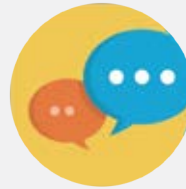
Sometimes we need a bit of space and distance to put things into context. Make time to reflect on your loved one's health and the impact on your past, present, and future story. If you feel comfortable doing so, share this with your loved one and his/her doctors so they better understand your perspective.



*Reframing your experience can help put things into perspective. Use the Reframe your Narrative worksheet on page 116 to consider a new, empowered narrative for yourself.*

### PEER-TO-PEER SHARING

Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others — either face-to-face or online — to share your story and listen to theirs.



*Support groups provide a safe and caring environment in which you can connect with others going through similar experiences. Check out the resources on page 164 to find a group that's right for you.*

### STORYTELLING WITH PURPOSE

Have you experienced something confusing, frustrating, or perhaps traumatic that others might be experiencing? Your story can help make change happen.



*See how others have used their stories to raise awareness on important healthcare issues in our Story Bank on page 148*





IF YOU FEEL **TRULY HOPELESS** —  
ENOUGH THAT YOU ARE CONSIDERING  
TAKING YOUR OWN OR SOMEONE ELSE'S LIFE —  
YOU CAN GET **IMMEDIATE HELP** BY CALLING A SUICIDE HOTLINE.  
YOU CAN REACH THE NATIONAL SUICIDE PREVENTION LIFELINE  
AT **800-273-TALK**.

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*Having trouble with  
**expressing yourself**  
with words?*

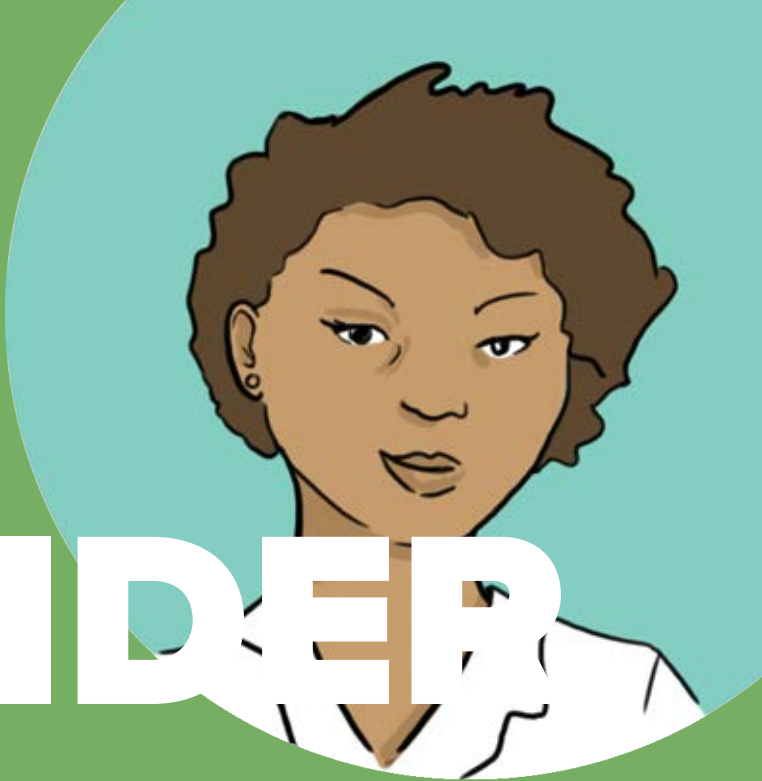


*Try using Expressive Arts to find your voice (pg 24).*



*I am a*

# PROVIDER



I CAN'T RELATE TO MY PATIENT.

MY PATIENT HAS A SERIOUS DIAGNOSIS.

I AM AT A LOSS WITH HOW TO PROCEED.

I FEEL STRESSED AND BURNT OUT.

PROVIDERS INCLUDE DOCTORS, NURSES, PHYSICIAN'S ASSISTANTS, CHAPLAINS, THERAPISTS,  
SOCIAL WORKERS, NURSE ASSISTANTS, PHARMACISTS, AND OTHER CLINICAL STAFF



*Do you remember the reason you went into healthcare? Do you remember the moment you realized the impact you could have on people's care and healing? Many of you were inspired by a person, a story, or an experience. Narrative and story are why you're here — they have been part of the human healthcare experience way before medicine became a profession. That's the power of narrative.*

So what if we told you that this playbook could help you filter the noise and find the clues that you're looking for in someone's health story? That it could help you and your patients make the best decisions for them and their circumstances, and in the process reduce time and costs from inappropriate surgeries, treatments, or care plans? That it could help all parties in a difficult patient-provider relationship to re-establish trust, respect, and rapport — as well as decrease the likelihood of lawsuits? Or that it could help you regain the passion and purpose that brought you into this field in the first place?

Guess what? It can... and we have evidence to prove it. This playbook can help you improve care, healing, and health by harnessing the power of narrative through simple and time-effective methods.





## **BUSTING BARRIERS TO NARRATIVE**

*Not convinced about the value of narrative in healthcare?  
Consider these reasons you for exploring these methods.*



**YOUR ARGUMENT:** Listening to patients' stories takes too much time.  
I only have eight minutes with each patient if I'm to meet my quota.



**OUR REPLY:** Building narrative methods into patient visits can done in very small, non-time-consuming ways. When uninterrupted, patients rarely talk for more than two minutes to share their health concerns. That's not much time, but that's all you need to provide them the opportunity to feel heard and provide more context for you.<sup>10</sup>

You can also make small tweaks to the ways you use your time in patient visits. Studies show that listening and probing for context doesn't take longer than visits that do not contextualize care. It's less about the time spent and more about how you listen to the small bit of story you do have time to hear.





**YOUR ARGUMENT:** I was trained to maintain objective distance from patients. Using narrative methods will make me more subjective, resulting in mistakes.



**OUR REPLY:** We know medical education has historically demanded that emotion and reason be separated. In fact, most medical students experience a decline in empathy by the third year of medical school.<sup>12</sup> However, there's ample evidence to reconsider this position. Studies show that provider empathy increases patient satisfaction while also decreasing the likelihood of malpractice suits.<sup>13 14</sup> When you building narrative and story into your practice, you can extend empathy and true caring into your practice well beyond medical school and throughout your career.





**YOUR ARGUMENT:** I can see how narrative and stories can contribute to better communication, but how can they provide better care, healing, and outcomes?



**OUR REPLY:** A recent Joint Commission report found that more than 70 percent of serious adverse health outcomes were caused by communication failures, rather than the provider's technical skill.<sup>15</sup>

Adding simple and effective narrative methods to your practice not only helps you understand how your patients make sense of their health conditions, it also improves healthcare outcomes<sup>16</sup>, reduces costs<sup>17</sup>, improves medical ethics, and decreases malpractice claims.<sup>18</sup>

Additionally, the narrative act of writing by itself brings huge benefits to patients, caregivers, and providers alike.<sup>19</sup> These benefits include improved health outcomes such as reduced blood pressure, fewer visits to the doctor, and fewer days spent in the hospital. It also improves social and behavioral outcomes such as reduced absenteeism, improved memory functioning, and higher grade point averages.







**YOUR ARGUMENT:** I'm not a touchy-feely person. I'm in the business of saving lives, not the business of writing.



**OUR REPLY:** Healthcare narrative isn't about, and doesn't mean, publishing a novel or writing a short story (but don't let that stop you!). Rather, it's about bringing into clinical practice the part of the brain that turns data into meaningful relationships and stories.

Even though clinical practice is predicated upon science, the humans involved — providers, patients, and caregivers — make sense of the world through stories.<sup>20</sup> Our brains are hardwired for story. Information and data do activate the language processing areas of the brain. But stories go further — they activate other brain areas and harness them to experience events as well.<sup>21</sup>

Narrative and medicine are inextricably linked. Call it touchy-feely, but harnessing your innate ability to extract, decode, process, and act upon stories will help you save more lives and help increase quality of life for more patients in ways that are beyond the limits of clinical interventions.





## NARRATIVE for EVERYDAY WELLNESS

*How to build a foundation of narrative into your healthcare practices.*

**CLINICAL NARRATIVE** (pg 22): Electronic health records, the primary tool for capturing key medical information, don't capture the patient's narrative, so the meaning gets lost. Bring meaning back into current data-heavy clinical tools and resources by building back in elements of the patient's story.

***Incorporating small, humanizing details*** into clinical care doesn't require a major process overhaul. Include personal reflections and quotations from your patient's story in his or her medical chart.

---

**LISTENING** (pg 20): Respect your limited time with patients by building in simple, effective ways to observe how the patients themselves make sense of their health conditions. This not only improves healthcare outcomes<sup>22</sup> and reduces costs<sup>23</sup>, but also fosters a greater sense of care and empathy between you and your patient.<sup>24</sup>

**Understand how to Listen for Context** and the impact it can have on your patients on page 125.



**JOURNALING** (pg 26): Daily journaling is a great way to review each day. These don't have to be long or complex reflections. Even quickly jotting down thoughts a few times a week can help you relive the joys, cope with the stresses, and process the trauma.

**Studies show** that journaling about stressful events — both what you felt and how it affected you as a person — can help you move beyond them.<sup>25 26</sup>

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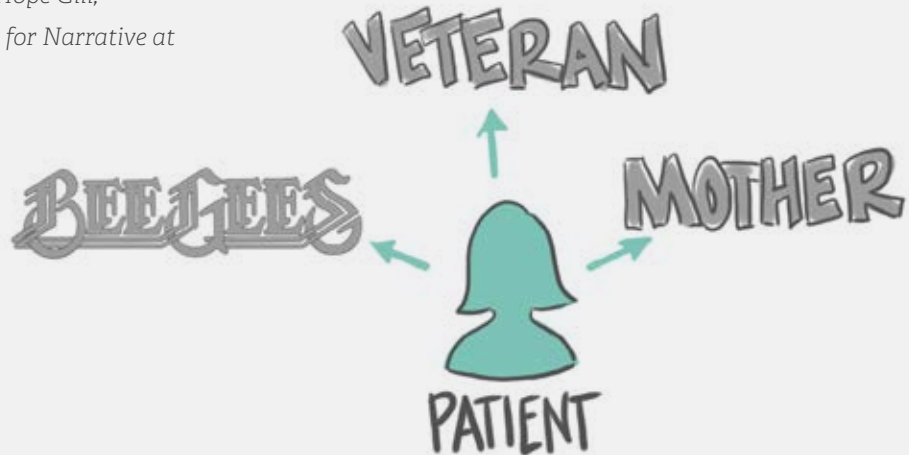
*Learn how others have built narrative into their daily practice in our Story Bank on page 127.*



## **“A cardiac surgeon stands at the operating table with his team.**

The patient is prepped for a triple bypass. The tools glint in the bright lights. Before making the incision to expose the patient’s heart, the surgeon tells his team the patient’s name, that she is an Iraq veteran, a mother of three, and that she likes the BeeGees. After the procedure is complete, his team tell him they wish every surgeon told a little story about the patient. They say it gave the surgery more meaning.”

*Inspired by stories told to Laura Hope Gill,  
Director of Thomas Wolfe Center for Narrative at  
Lenoir-Rhyne University*



***I'm not sure  
how to relate  
to my patients  
and/or their  
caregivers.***



*PERHAPS...*

*I feel like a patient isn't listening to my recommendations.  
Some of my patients don't seem to trust the medical system.  
I have patients that feel they have experienced discrimination.  
I feel misunderstood and sense some of my patients do too.  
I am just not connecting with my patient(s).*





## ***“My first efforts at writing about the doctor-patient relationship***

sounded more like articles from the New England Journal of Medicine...The cold, distancing language of medicine had crept in and locked out feeling.”

*David Watts from “Bedside Manners: One Doctor's Reflections on the Oddly Intimate Encounters Between Patient and Healer”*

# TRY OUT...

## LISTENING

Your time as a provider is very limited. But by building in simple and effective ways to attend to your patients and how they make sense of their health conditions, it not only improves healthcare outcomes<sup>27</sup> and reduces costs<sup>28</sup>, but it also improves medical ethics and decreases malpractice claims.<sup>29</sup>



*When uninterrupted, most patients finish presenting their concerns after just two minutes.<sup>30</sup> Build in a rule of thumb to let them tell their story, uninterrupted, for the first few minutes of a visit to build rapport and make them feel “heard”.*

## PERSONAL NARRATIVE

Sometimes we need a bit of space and distance to put things into context. Make time to reflect on what’s happened and how that has impacted your past, present, and future story. If you feel comfortable doing so, share this with others—including your patient—so they better understand your perspective.



*Reflect on why you decided to go into the medical field in the first place. What drew you to this work? How does that relate to this current situation? Are you staying authentic to your mission as a provider?*

## PEER-TO-PEER SHARING

Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others – either face-to-face or online – to share your story and listen to theirs.



*For provider-specific online communities, check out [Doximity.com](https://www.doximity.com), [Sermo.com](https://www.sermo.com), or [Doc2Doc.bmj.com](https://www.doc2doc.com).*





# SILENCE

*can mean so much.*

WHAT THE PATIENT OR CAREGIVER LEFT OUT  
*can reflect gaps in understanding*  
OR SIGNAL SOME TRAUMA OR SOCIAL TABOO.



---

SOME HEALTHCARE SYSTEMS AND HOSPITALS HAVE USED  
**“MEDICAL MISTAKES PLAYBACK THEATER”** —

*improvisational re-enactments of real-life stories —  
to facilitate discussion and build  
communication and problem-solving skills.*



LEARN MORE ABOUT HOW IT WORKS ON PAGE 118.

***My patient  
has a serious  
diagnosis.***



*PERHAPS...*

*I'm not sure how I can break bad news gently.*

*I'm worried how they will take the news.*

*I need to make sure they have the right information and expectations.*

*I don't know how I can help them through this transition.*

*I'm wondering if they have the right support in place.*

*I want to make the best decisions together.*





***“When people experience traumatic news,***

they frequently go into a cognitive or emotional fibrillation (e.g., kinetic, repeated movement, thoughts, talking that is not productive). They can't move forward to make smart choices — they're stuck. By listening, staying mostly silent, and collecting the pieces of insight and information that emerge, together you can feel your way through strategic plans that they can grasp.”

*Advice from patient advocate*



## TRY OUT...

### LISTENING

Your time as a provider is very limited. But by building in simple and effective ways to attend to your patients and understand how they make sense of their health condition, healthcare outcomes will improve<sup>31</sup>, costs reduce<sup>32</sup>, malpractice claims decrease, and medical ethics improves.<sup>33</sup>



*If you have trouble understanding what your patients are thinking or experiencing, use the Facilitated Storytelling prompts on page 123 to help them share their story.*

### CLINICAL NARRATIVE

Electronic health records are the primary tool for capturing key medical information about patients, but their narrative — and therefore, their meaning — gets lost. Bring meaning back into data-heavy clinical tools and resources by building back in elements of the patient's story.



*Your patient will likely have many people on his or her care team. Do your part to coordinate decision-making by capturing the pieces of their story to share among providers.*

### JOURNALING

Daily journaling is a great way to review each day. These don't have to be long or complex reflections. Even quickly jotting down thoughts a few times a week can help you relive the joys, cope with the stresses, and process the traumas.



*Providers experience grief along with their patients, though it's rarely discussed. Unacknowledged grief can lead to negative consequences in terms of health care and personal lives.<sup>34</sup> Make space for processing your own feelings through reflection.*





## *People don't listen well when they feel ill or are receiving bad news*

AND ESPECIALLY NOT WHEN THE TWO ARE COMBINED.



HELP THEM REMEMBER KEY PARTS OF YOUR CONVERSATION  
BY ASKING THEM TO RECOUNT WHAT THEY HEARD.

*If they are confused or missed something,  
write it or audio-record it for them.*

---

Contrary to popular belief,

## ***finding contextual clues in a patient's story***

doesn't take more time during a visit.<sup>35</sup> It's just a better use of your time.

Think quality, not quantity.



***I'm at a loss  
for how to  
proceed with  
a patient.***



*PERHAPS...*

*Their treatment plan isn't working.*

*I feel like I've exhausted all options.*

*I'm stuck.*

*I feel like I'm failing them.*

*This isn't how it's supposed to be.*

*I'm trying to figure out how to tell them, "I don't know."*





There are so many benefits to electronic medical records, but as Danielle Ofri mentions in her 2010 New York Times article, “The Doctor vs. The Computer”

“The system encourages fragmented documentation, with different aspects of a patient’s condition secreted in unconnected fields, so it’s much harder to keep a global synthesis of the patient in mind.”

*Using Narrative Methods can help bring that global perspective back.*



## TRY OUT...

### PERSONAL NARRATIVE

Sometimes we need a bit of space and distance to put things into context. Make time to reflect on what's happened and how that has impacted your past, present, and future story. If you feel comfortable doing so, share this with others—including your patient—so they better understand your perspective.



*Reframing your role in the context of this situation can help put things into perspective. You can use the Reframe your Narrative worksheet on page 116 to think through how this fits into your personal narrative.*

### EXPRESSIVE ARTS

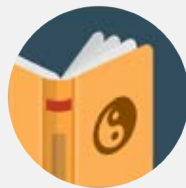
Sometimes it's hard to put our feelings into words. By using expressive arts—such as drawing, painting, dance, poetry, and theater—in a group setting, you can process what you are experiencing in a supportive atmosphere.



*There are workshops that help providers and patients work together. Check out these different formats of facilitated expressive arts on page 118.*

### INDIVIDUALIZED LEARNING

Search books, articles, videos, films, and online resources to find information that you relate to, even if it's not about the same condition or challenge. Learning from such resources may be cathartic, and can help us understand how others feel and get an idea of how to proceed.



*We've provided a recommended reading list on page 165.*



*When you feel you have*

**EXHAUSTED**

*your tools & resources,*

and have nothing more to offer your patient  
remember that you have one more offering:



**“BEARING WITNESS”**

to their experience in a show of compassion &

**SOLIDARITY.**



FIND FILMS  
OR *stories*



***about health challenges***

***your patients are facing.***

Not only are these cathartic,

***they can enrich our understanding***

from their perspective.



***I feel completely  
stressed and  
burnt out.***



*PERHAPS...*

*My patient isn't getting better.*

*I feel defeated.*

*I feel powerless over my life.*

*I'm dealing with dark moments.*

*I feel traumatized by what I've experienced.*

*I feel lost.*

*I feel scared.*

*I feel confused.*

*I feel alone in the challenges I'm facing.*



## ***“An E.R. nurse ends a 12-hour shift feeling as though he has witnessed a war.***

Patients have flown through the doors so quickly and in such degrees of trauma that he has had to turn himself into a machine in order to just get all the vitals down and the patients admitted. As he walks out of the hospital, he looks up and sees a bright, full moon. Its edges blur. He realizes he is crying. He lowers himself into his car and drives home. Once there, even though he is exhausted, he does not go immediately to bed. He sits at his dining room table with a cup of tea and writes one short letter he will never send. It is to the patients he saw and will probably never see again. He engages in this practice at the end of every shift as a way of processing and coping with the heartbreak he experiences each day.”

*Inspired by stories told to Laura Hope Gill, Director of Thomas Wolfe Center for Narrative at Lenoir-Rhyne University*



## TRY OUT...

### PERSONAL NARRATIVE

Sometimes we need a bit of space and distance to put things into context. Make time to reflect on what's happened and how that has impacted your past, present, and future story. If you feel comfortable doing so, share this with others—including your patient—so they better understand your perspective.



*Writing about difficult and traumatic events not only helps you process them, but may lead to better health.<sup>36</sup> Use the prompt on page 124 help you explore your feelings.*

### PEER-TO-PEER SHARING

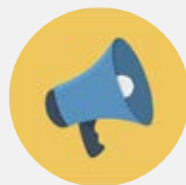
Need ideas from others with similar challenges? Interested in having your feelings validated? Reach out to others — either face-to-face or online — to share your story and listen to theirs.



*Support groups can help you connect with others going through similar experiences in a safe and caring environment. Check out the resources on page 164 to find a group that's right for you.*

### STORYTELLING WITH PURPOSE

Have you experienced something confusing, frustrating, or perhaps traumatic that others might be experiencing? Your story can help make change happen.



*See how others have used their stories to raise awareness on important healthcare issues in our Story Bank (pg 148).*





## IF YOU FEEL TRULY HOPELESS —

enough that you are considering taking your own or someone else's life — you can get immediate help by calling a suicide hotline.

**You can reach the National Suicide Prevention Lifeline at 800-273-TALK.**

---

HAVING TROUBLE WITH EXPRESSING YOURSELF WITH WORDS?

Try using *expressive arts* to find your voice (pg 24).





# WORKSHEETS





# WHO I AM WORKSHEET

**WHAT WAS THE** *best decision you've ever made?*

**WHAT ARE THE** *most important things in life?*

**WHO ARE THE** *most important people in your life right now?*

Three horizontal grey bars for writing answers to the question about important things in life.



A large dotted-line box for writing answers to the question about important people in your life.



**WHAT WAS THE** *hardest decision you've made?*



**WHAT DO YOU CONSIDER TO BE YOUR** *strongest character traits?*

A large dotted-line box for writing answers to the question about strongest character traits.

**IF YOU COULD** *do anything over in your life,*  
**WHAT WOULD IT BE,**  
*and what would you do differently?*

A grey-shaded box for writing answers to the question about doing anything over in your life.

**WHAT ARE YOU MOST PROUD OF?**



A dotted-line box for writing answers to the question about what you are most proud of.

**WHAT ARE** *five things you couldn't live without?*

Five grey circles arranged horizontally for writing answers to the question about things you couldn't live without.

**WHAT WOULD PEOPLE BE** *surprised to learn about you?*



A large dotted-line box for writing answers to the question about what people would be surprised to learn about you.

**WHAT DO YOU** *hope to be remembered for?*

A dotted-line box for writing answers to the question about what you hope to be remembered for.

Use this worksheet to reconnect you to your life story – past, present, and future. This can be used as a foundation for building, processing, and sharing important points about your own narrative. You can reflect on and answer these questions all at once, if you have some time, or you can complete them as needed. You can write your answers down, do an audio and/or visual recording, or use these as starting points for expressive art, such as collages, poems, songs, etc. Either way, these prompts are meant to reconnect you to who YOU are.



# WHAT I HEARD DURING MY APPOINTMENT WORKSHEET



WHAT IS THE *goal* of your visit?

APPOINTMENT DATE

TIME

NAME OF DOCTOR



WHAT PROBLEMS OR ISSUES  
*are you addressing?*



WHAT DOES YOUR DOCTOR  
*recommend doing?*



## MEDICATION PLAN

MEDICATION NAME	DOSAGE	WHAT'S IT FOR	WHEN TO TAKE

Most times, the information given during doctor's visits happens through a fast conversation and a lot can be forgotten after you leave your appointment. **Use this worksheet during your appointment** to help focus your listening, and to remember and reflect on what you heard. **Before leaving, review this with your doctor** to make sure you are both clear on what your plan is moving forward.

**WHOM SHOULD YOU CALL if your doctor isn't available?**

## CARE PLAN

**WHAT SHOULD YOU SAY?**

WHAT GOALS *are you working toward?*

WHAT IS YOUR DOCTOR *responsible for doing?*

WHAT ARE YOU *responsible for doing?*

WHAT OTHER SERVICES *are needed?*

WHAT SHOULD YOU DO AT HOME *to manage your health?*

## EMERGENCY PLAN



### TIP

Ask your doctor whether it's ok to audio or video record your conversation, either on your phone or through apps like MyDocNotes. That way, you can capture what was said to listen to it later.

**WHAT COMPLICATIONS should you look out for?**

**WHAT SHOULD YOU DO if complications arise?**



# REFRAME YOUR NARRATIVE WORKSHEET

It can be difficult to stay focused on the future when you encounter difficulties. Use this worksheet to reframe your journey as a Hero's Journey to transform your story into a powerful narrative. Rather than feeling defeated by your challenge, ask yourself, "What's the opportunity before me?"



Hero's Journey stories appear in all cultures, but their underlying character, plot, and structure are much the same. On the left, we have the typical Hero's Journey story. On the right, fill in aspects of your past, present, and potential future – and how you might reframe your Hero's Story to overcome the health difficulties you are currently experiencing.

## THE HERO'S JOURNEY

**The hero is in a stable place.**

*How was your life before you encountered difficulties?*

**Something breaks the hero loose.**

*What happened to shake up your world?*

**The hero goes into a difficult period.**

*What challenges did you face as a result, and how did that affect your life?*

**The hero emerges from that dark period and goes on a journey to accomplish great things, meet daunting challenges, and reach a desired destination.**

*What's your current journey?*

**The hero experiences tests along the way.**

*What are future challenges you foresee?*

**The hero passes the tests, achieves the goal, meets the daunting challenge, and reaches the desired destination.**

*What's the ideal vision for your future?*

*Where do you want to end up?*

## YOUR LIFE'S JOURNEY (PAST, PRESENT & FUTURE)





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# DIY EXPRESSIVE ARTS WORKSHEET



## **DRAW OR PAINT YOUR EMOTIONS.**

*What colors are you drawn to? what shapes depict what you are feeling?*

Expressive arts doesn't take training. It just takes an open mind and a little exploring. Try out a few of the following exercises to help you find your voice, process your experience, and ultimately, heal.

## **DESIGN A POSTCARD YOU WILL NEVER SEND.**

*Are you angry, upset, or frustrated with someone? Has something impacted your life that completely changed it? Create a postcard that expresses this, though you don't have to ever send it.*

## **COLLAGE YOUR VISION OF A PERFECT DAY.**

*Think about what makes a perfect day to you and use magazines or photos to create it. What about this collage can you make happen today?*

# FACILITATED EXPRESSIVE ARTS REFERENCE SHEET

Using artistic ways of processing your story and expressing yourself can have powerful effects – particularly if they are led by an experienced facilitator. Consider the following methods for using expressive arts in a workshop setting.

## NARRATIVE WRITING WORKSHOP

### *What is it?*

These workshops can range from reading a piece of text or poem and discussing it, writing based on prompts, or crafting their own stories.

### *What are the benefits?*

- Providing the safety, space, and time to craft a personal narrative
- Increasing empathy and communication through understanding others' perspectives
- Building community among medical professionals and ameliorating burn-out
- Reconnecting with humanity and hope

### *What does this look like in action?*

- Teaching Psychiatric Patients Writing, and Hope: <http://nyti.ms/1EYkYmQ>
- Warrior Voices: <http://nyti.ms/1MGGDH5>
- Medical professionals increasingly turn to poetry, literature to improve patient care: <http://bit.ly/1Gkr9TN>

## INTERACTIVE THEATER/PARTICIPATORY THEATER

### *What is it?*

A variety of theater formats or approaches to prompt discussion, reflection, and critical dialogues — particularly for “silent” populations, such as children, elderly, and vulnerable groups. Because it is typically done in a group setting, it boosts feelings of validation and confidence.

### *What are the benefits?*

- Bringing to light issues of social/political issues, power, privilege, bias, and assumptions in small group settings (i.e., Engaged Theater)
- Practicing action towards real social change through theater games, activities & discussion (i.e., Theater of the Oppressed)
- Identifying, analyzing, and responding to “internalized oppression” in order to better understand its origins (i.e., Rainbow of Desire)
- Facilitating new perspectives and physically working through challenges through role playing (i.e., Psychodrama)
- Revisiting difficult conversations and understanding how they could have been better (i.e., Playback Theater)
- Recalling memories and acting out stories with older populations around a particular moment in history — personal or cultural (i.e., Reminiscence Theater)
- Educating and enhancing learning through improvised role playing and expression of emotions — particularly in children (Child Drama, Creative Drama, Story Drama)

### *What does this look like in action?*

- Trauma Fuels HIV Epidemic Among Women: <http://bit.ly/19N0hzj>
- Use of interactive theater for faculty development in multicultural medical education: <http://bit.ly/1CW3SGD>
- Theater Program Uses Drama to Teach Kids about Health Issues: <http://bit.ly/11V7TMn>

## EXPRESSIVE THERAPY/ CREATIVE ARTS THERAPY

### *What is it?*

Using the creative arts - personal writing, spoken word, painting, dance, music, or theater – to create a performance. Participants are encouraged to explore their responses, reactions, and insights based on their experiences.

### *What are the benefits?*

- Stress reduction & personal healing
- Increased depth of communication
- Discovery of new insights, opening unarticulated feelings, and shedding light on the past
- Building confidence and feelings of validation - especially in a group setting

### *What does this look like in action?*

- Finding your compass: <https://vimeo.com/93264018>
- The Power of Art in Healthcare: <http://bit.ly/1NL1Z30>
- Music in the Emergency Department: <http://bit.ly/1HngKFO>



# IMPORTANT ASPECTS OF MY LIFE WORKSHEET

Use this worksheet to keep your provider updated about any changes in your life so, together, you can make sure your care is appropriate to your life. Fill it out before your appointment, share aspects that you think are important for your doctor to know, and save it afterwards so you can refer to it when you prepare for your next appointment.

**IN GENERAL, WHAT'S BEEN GOING ON IN YOUR LIFE RIGHT NOW?**

**CHANGES IN RELATIONSHIPS  
(PARTNERS, HOUSEHOLD MEMBERS/FAMILY, FRIENDS/SUPPORT SYSTEM)**

**CHANGES IN LIFESTYLE (JOB/EDUCATION, CHILDCARE,  
TRANSPORTATION, SOCIAL SUPPORT, PHYSICAL ACTIVITY)**

**CHANGES IN FINANCES  
(INCOME, MAJOR EXPENSES, JOB STABILITY, COST OF LIVING)**

**CHANGES IN NEIGHBORHOOD  
(NEIGHBORS, CRIME, RECENTLY MOVED, NEW/CLOSED SERVICES)**

**CHANGES IN HEALTH  
(SLEEP PATTERNS, FOOD, HEALTH INSURANCE, MOOD, PHYSICAL ISSUES)**



# HEALTH INFORMATION ORGANIZER

These days, there's so much being published on different conditions and illnesses. You can learn how others have navigated the experience through books, such as illness narratives or memoirs, newspaper and magazine articles, or films about health challenges. To manage information overload, we've provided a simple way to keep your thoughts organized.

## MAIN THEMES OR IDEAS

## THINGS YOU LEARNED THAT RESONATED WITH YOU

## THINGS YOU LEARNED THAT SURPRISED YOU

## NEW QUESTIONS OR TOPICS TO EXPLORE





# EFFECTIVE STORYTELLING REFERENCE SHEET

Doctor appointments are often fast and brief -- and that's not the doctor's fault, but thanks to our healthcare system. Effective storytelling can help us make the most of the time we have with our care team. Help communicate important points about yourself clearly and effectively with these tips.

## **FIRST, TAKE A MOMENT TO UNDERSTAND YOUR APPOINTMENT FROM YOUR DOCTOR'S POINT OF VIEW.**

Your doctor wants to help you. That's why they are in this profession in the first place. But he or she has to deal with short appointments, fear of making a mistake and getting sued, and endless paperwork.

## **BUT WHAT ARE DOCTORS THINKING DURING YOUR VISIT?**

Lucy Hornstein wrote a wonderful write up on KevinMD.com about how it's about recognizing the "right" story the patient is telling.<sup>1</sup> Here are a few excerpts:

*"[As a doctor], imagine that someone is telling you a story. There are lots of different stories it could be, but the person has no idea which one it is. In fact, as far as he's concerned, no one has ever heard the story before because it's the first time he's telling it. But he's telling it to you because he's hoping you'll recognize the story, and tell him how it's going to end — or, more importantly, intervene to change the ending, if it happens to be a story that ends badly.*

*continued...*

### **HOW TO TELL YOUR STORY EFFECTIVELY.**

Here's how you can help your doctor identify your story.

What brings you here today? Try to keep it to one sentence – short and sweet. If you have more than one concern, start with the main one first.

#### **TELL YOUR STORY (NOT YOUR SYMPTOMS).**

- Start at the beginning – when did your symptoms start?
- How have they changed, and when did they change? Have any new issues started?
- What effects have your health problems had on your life? (Give real examples, such as “The pain is so bad that I’ve missed the past four days of work” or “I can’t climb stairs because I lose my breath so easily.”)
- How has this made you feel?

#### **SHARE YOUR IMPRESSIONS.**

- What do you think is causing these issues?
- What seems to make it better or worse?
- What are you most concerned about?

### **ASK YOUR DOCTORS TO SHARE THEIR THOUGHTS.**

Ask them, “At this point, what are you thinking?” If they misinterpreted or missed something, you have the chance to clarify.

#### **IS THE APPOINTMENT NOT GOING AS PLANNED?**

Try to use non-defensive “I statements” when you’re confused or frustrated. Be direct, but polite—tone makes a huge difference in getting others to listen. It may sound gimmicky, but it gets people’s attention and can’t be argued with.

- “I’m worried about my health so I want to make sure you have correct information.”
- “I don’t understand what you’re telling me.”
- “I missed that last part—can you explain it one more time?”
- “I’m having trouble following this conversation.”
- “I’m unsure why I need to change medications.”
- “I would like to come to appointments on time, but don’t have reliable transportation.”
- “I can’t afford this treatment. What can we do about that?”



# FACILITATED STORYTELLING REFERENCE SHEET

As a provider or caregiver, you can ensure your patients and their loved ones get the care they want and need by helping them share their story. By facilitating their narrative – prompting them to tell important pieces of their story – you can make them feel heard while eliciting relevant information for making decisions about their diagnosis, care, and ability to heal.

A facilitated narrative doesn't have to be a heavy lift. It can come in the form of a five-minute dialogue, or a targeted questionnaire that patients can fill out before their appointment. It can be used with children, seniors with cognitive issues, terminal patients, or patients with complex medical history.

## CONSIDER USING THE FOLLOWING PROBES OR TECHNIQUES TO STIMULATE A CONVERSATION.

**For understanding the patient's perception**

*"What is your understanding of your illness or condition?"*

**For tapping into their emotions & motivations around their health**

*"What are your goals and priorities?"*

*"What are your worries or fears for the future?"*

*"What would a good day look like?"*

**For understanding their needs – where they draw a line for medical treatment**

*"What outcomes are unacceptable to you?*

*What are you willing to sacrifice and not?"*

**For end of life planning**

*"To you, what would a good death look like?"*

*"Where would you want to be for the end of your life? Who would be with you?"*

*"Is it more important to be aware and lucid, or being out of pain?"*

*"How do you want to be remembered?"*

**For eliciting negative experiences from their past in order to move into a more productive relationship**

*"Tell me about a time when you felt intimidated by the healthcare system.*

*What contributed to your feeling that way?"*

**For eliciting positive experiences from their past that provide a foundation for relationship building**

*"Tell me about a time when you felt heard and respected by a healthcare provider.*

*What helped you feel that way?"*

**For gently accessing information about belief & faith**

*"What gives you meaning and comfort?"*

**For those with memory problems**

*Use photos to bring creative engagement to those with memory loss.*

*See Anne Bastings' TimeSlips: [www.timeslips.org](http://www.timeslips.org)*

# DAILY REFLECTION REFERENCE SHEET

Write down thoughts and feelings after each day.

Patients and caregivers could do this especially after important news about their personal or loved one's health. Providers could write about sentinel events and or other difficult experiences.

## TYPES OF JOURNALS:

Here are a few suggestions for different types of journals you can keep.

### *Appointment Days:*

Write down thoughts, feelings, and what you remember about your visit after each appointment you have with your care team. Not only will this help you remember what was said during the appointment, but it will help you process your thoughts and feelings, which can help with decision-making.

### *Health Journal:*

Track key aspects of their health and relevant aspects of your life outside clinical settings. It can facilitate communication by creating an unintrusive connection between you and your provider as well as highlight key patterns in habits or behaviors that may be impacting your health. Use it to track daily fluctuations in mood, health symptoms, meals, sleep patterns, stressful events, and medication changes.

### *Sketch or Collage Journal:*

Draw or choose an image that represents how you feel each day, with a few notes about your experience.

### *Positivity Journal:*

Make a note of all the great things you do every day, and look at it whenever you need a personal lift. They don't have to be a big deal—even if they're things like “woke up feeling rested for the first time in ages,” or “chose a salad over pizza for lunch,” as they accumulate, you'll have plenty of ammo to look at every time you're feeling down or like you can't do anything right. It'll feel silly at first, but the first time you open it and crack a smile when you're having a hard day, it'll be worth having.

### *Stress Journal:*

Psychologist James Pennebaker uses this writing exercise to help people work through stress. It's shown to have health benefits and enables better coping. For 15 minutes each day, write about your deepest emotions and thoughts about the most upsetting experience in your life.

“Really let go and explore your feelings and thoughts about it. In your writing, you might tie this experience to your childhood, your relationship with your parents, people you have loved or love now, or even your career. How is this experience related to who you would like to become, who you have been in the past, or who you are now? Many people have not had a single traumatic experience but all of us have had major conflicts or stressors in our lives and you can write about them as well. You can write about the same issue every day or a series of different issues. Whatever you choose to write about, however, it is critical that you really let go and explore your very deepest emotions and thoughts.”

Pennebaker, J.W. (2004). *Writing to Heal: A Guided Journal for Recovering from Trauma and Emotional Upheaval*. Oakland, California: New Harbinger.

## TIPS FOR WRITING:

- Find a time and place where you won't be disturbed.
- You can write longhand or you can type on a computer. If you are unable to write, you can also talk into a tape recorder.
- Once you begin writing, keep your hand moving and write continuously. Don't worry about spelling or grammar. If you run out of things to write about, just repeat what you have already written.
- Many people report that after writing, they sometimes feel somewhat sad or depressed. This typically goes away in a couple of hours. If you find that you are getting extremely upset about a writing topic, simply stop writing or change topics.



# LISTEN FOR CONTEXT REFERENCE SHEET

## FOR PROVIDERS

*A woman being scheduled for gastric bypass surgery commented that she looked forward to losing weight so that she could get around more easily and better assist her son who is disabled. Concerned about the passing reference to her caretaking responsibilities, the physician asked her about her disabled son. He was aware that abdominal surgery for obesity can be fraught with complications, and average recovery time was 46 days. In the discussion that followed, the patient described how she was the sole functioning adult member of her household at a critical time. As they discussed her home situation and her plans for surgery, she expressed dismay at the thought of being unable to care for her children for weeks or months. "They need me now more than ever," she said. The physician also pointed out that assisting her son with toileting and bathing, which required heavy lifting, could complicate her recovery. She noted that she had been informed about the possibility of a lengthy post-operative course, but had been focused on the positive aspects of surgery, particularly greater mobility. She concluded, and the physician concurred, that this was the wrong time for the procedure.*

In the story above, the patient's doctor had discussed the surgery with her and she had indicated her preference, yet no one had identified the incongruity between her current life context and the proposed plan of care. A solution would be to listen for context -- identifying what is relevant to the immediate clinical problem from across the spectrum of a patient's life -- in order to contextualize her care.

Typically, providers are trained to listen for biomedical red flags during clinical encounters with patients, yet are not trained to listen for contextual red flags that may have a great impact on their diagnosis and care plan.<sup>12</sup> During a time-limited visit (and all clinical encounters are time-limited), listening for context allows providers to identify and address those aspects of a patient's narrative that have practical implications for what to recommend they do next in planning their care.

During clinical encounters with patients, listen for contextual clues in a patient's story that may impact their care and ability to heal. This brief overview covers the work of Saul J. Weiner and his colleagues at the University of Illinois at Chicago.

*continued...*

## THE FOUR STEPS FOR CONTEXTUALIZING CARE ARE TERMED, RESPECTIVELY:

### 1. Listening for contextual red flags.

These can include medication adherence issues, misunderstanding of clinical protocols, challenges with following orders, and discrepancy in biomedical readings.

*For a patient who has lost control of his asthma, the comment, "Boy, it's been tough since I lost my job!" is a clue that the patient may be having financial and/or other difficulties that could account for loss of control of his or her chronic condition.*

### 2. Probing the contextual red flags.

Asking a direct open-ended question that addresses a red flag, such as "Why do you think this is happening?" or "What could be contributing to this?" Red flags can also be probed by making a statement that demonstrates awareness of red flag (e.g., "Your A1c has gone up since last Time."), with the intent that the patient will provide a contextual factor.

*The provider, hearing that clue, replies: "I'm sorry to hear that. What are some of the challenges you are facing?"*

While this reference sheet is meant to provide a general overview of the concept, you can learn more about this process, including how to train and code encounters for contextualizing care<sup>3</sup>, please review the references provided.

Ultimately, identifying contextual factors and addressing them in a patient's care plan has been shown to improve health care outcomes<sup>4</sup> and reduce costs<sup>5</sup>, making a strong case for how narrative listening methods produce positive impacts on care, healing, and outcomes.

### 3. Listening for contextual factors.

A contextual factor is a specific life challenge that accounts for presenting problem. Most contextual factors fall under one of the following categories.

- Competing responsibilities: "I take care of a sick relative" or "I can't get off work for appointments."
- Social support: "My wife works and can't help me with my ..."
- Access to care: "I live far away from the clinic and don't have a car."
- Financial situation: "I don't work and can't afford..."
- Skills, abilities and knowledge: "I don't understand..." or "I have bad eyesight and can't see med bottle print."
- Emotional state: "I've been too upset to keep track of my medications."
- Cultural perspective/spiritual beliefs: "Where I come from, we just go to the doctor when we are sick." "I don't need treatment, God will heal me if it is his will."
- Environmental issues: "I live in a nursing home and have to eat the food they give me."
- Attitude toward illness: "Diabetes is not that big of deal, I can eat what I want."
- Relationship with health providers: "I don't trust doctors."

*The provider then listens for a response, such as "Yes, I've lost my health insurance and can't afford this expensive medicine I'm taking."*

### 4. Contextualizing care.

Addressing the contextual factors in the care plan in order to overcome the obstacles, such as providing a list of medications as well as when to take them, prescribing a cheaper generic medication, or moving their care to a closer clinic.

*Finally, the clinician considers how that information could inform planning care. In this case, switching the patient to a less costly generic medicine could address or mitigate the challenge of affording the medication.*

1. Weiner SJ. Contextualizing medical decisions to individualize care: lessons from the qualitative sciences. *J Gen Intern Med.* Mar 2004;19(3):281-285.

2. Weiner SJ. From research evidence to context: the challenge of individualizing care. *ACP J Club.* Nov-Dec 2004;14(3):A11-12.

3. Weiner SJ, Ashley N, Binns-Calvey A, Kelly B, Sharma G, Schwartz A. Content Coding for Contextualization of Care: Training & Coding Manual. Harvard Dataverse Network. [dvn.iq.harvard.edu/dvn/dv/4C](https://dvn.iq.harvard.edu/dvn/dv/4C) (last accessed 11.11.2014).

4. Weiner SJ, Schwartz A, Sharma G, et al. Patient-centered decision making and health care outcomes: an observational study. *Ann Intern Med.* Apr 16 2013;158(8):573-579.

5. Schwartz A, Weiner SJ, Weaver F, et al. Uncharted territory: measuring costs of diagnostic errors outside the medical record. *BMJ Qual Saf.* Jul 7 2012.



# STORY BANK



SORTED BY METHOD TYPE AND **PATIENT** / **CAREGIVER** / **PROVIDER**



## **PATIENT** | Personal Narrative | Listening

“At the age of 36, I was diagnosed with lupus and told by a physician who didn’t know a great deal about it that I had only about a year or two to live. I learned three valuable lessons from the experience. First, that life is very precious and not something to be taken for granted. Second, that my illness didn’t just affect me; it had a major impact on every member of my family. And third, that dealing with the psychosocial aspects of an illness, such as the reactions of others, often was far worse than dealing with the physical issues. The only way that I got through this dark time was to write about what I was feeling. The process of writing helped me better understand and make sense of what was happening. From time to time I would look back on previous writings for an indication of progress. I remember the day when I finally could see that I was no longer in that dark place.”

Judy Rollins, RN & President of Rollins & Associates, Inc.  
and Adjunct Assistant Professor, Georgetown University School of Medicine





## **PATIENT** | Personal Narrative

“My orthopedist delivered the news that I needed knee replacements with his head hung low. ‘I hate to tell you this, because you’re so young,’ he said. My response was to reframe the issue for him. ‘I was only 13 when I was diagnosed with my first chronic condition, only 24 with my second illness, so if I am only 44 for this, that is okay.’ With that, we both were able to move ahead to make the best decisions we could together to optimize our knee replacement experience, unencumbered by guilt, shame, or sadness.”

Donna Cryer, President & CEO of the Global Liver Institute

## **PATIENT** | Personal Narrative | Journaling

“A young woman suddenly loses her husband in a tragic accident. Her colleagues and friends are impressed at how smoothly and courageously she seemed to be handling it. But on the inside, she felt lost, broken, and alone. She wasn’t sure how to deal with his death until she happened upon a local writing workshop. ‘What the heck,’ she thought, and signed up for the four-day session. By the last day of the workshop, she felt completely transformed. The writing experience made her realize she was on a life path she no longer wanted, and she had been putting on a false, cheerful front with her friends. Within two months, she quit graduate school and moved back to her hometown. While some may say that it sounds like a failure, from her perspective it wasn’t. In fact, the woman felt that those four days of writing had saved her life.”

Adapted from Dr. James W. Pennebaker’s *Writing to Heal*



## CAREGIVER | Personal Narrative

Writing helps me overcome isolation. A caregiver in one of my groups said she had to do her mountain climbing and that's what she did to overcome isolation. She got someone to take care of her husband and went mountain climbing. Do what you love: if you're a dancer, dance. If you're a singer, sing. Everybody can sing. That's one thing I don't do without Abe. I think I should sing more. My mother used to sing all the time. Maybe I'll start singing. I'll put some Joan Baez on."

From a 2013 Alzheimers.net interview with Esther Altshul Helfgott,  
author of *Dear Alzheimer's: A Caregiver's Diary and Poems*

## PROVIDER | Personal Narrative | Journaling

"My first efforts at writing about the doctor-patient relationship sounded more like articles from the New England Journal of Medicine...The cold, distancing language of medicine had crept in and locked out feeling."

David Watts from *Bedside Manners:  
One Doctor's Reflections on the  
Oddly Intimate Encounters Between Patient and Healer*



## CAREGIVER | Personal Narrative

“A future without you is weighing heavy on me. It’s hard to separate the patient from the person, and that’s not fair to you, but sometimes, I forget that your spirit is untouched... it’s just the body that’s having issues. But it’s the body that might not be with me in the end.

To some degree, I’m mourning the loss of you prematurely, but once I’m past this, I’ll be able to appreciate the indeterminate amount of time we have left.

And yes, you warned me of all of this. I didn’t heed the warnings. I guess faith gets in the way sometimes.

In some way, I need to overcome the loss of potential — of potential in the future, trips, thoughts — and then, I’ll be okay. Not that we still don’t have a ton of potential left.

It’s a lot to chew on at the moment... please don’t hold that against me.”

A letter from a caregiver to his loved one

## CAREGIVER | Personal Narrative

“As my mom deteriorated from Alzheimer’s, she was less and less participatory, so the challenge was to remember I was there to help her and at the same time allow the providers space to do their jobs. One very exceptional nurse pointed out that if I was spending my time documenting her daily habits, then how could I be engaging with her as her son?”

Bill Hill, Founder of Experience Design, Inc.



## PROVIDER | Personal Narrative | Listening

“When I first see a new patient, to know their story, I ask them where they live. Fifteen years ago, I met a tobacco farmer from near the Kentucky-Tennessee line. As a surgical oncologist, I was seeing him for his diagnosis of pancreatic cancer. I offered him an extra firm handshake that quickly wilted under a half-century of wrapping tobacco.

A few days later, he and I left the operating room together after several hours of removing his tumor from a cast of nerves and vessels. The next morning, he extended his hand with the same hearty grip.

On his post-op visits, we often talked of planting tobacco or the upcoming harvest, trying not to focus on the very real possibility that his cancer could come back. One day, he gave me a gift that I will always cherish, a cured bundle of tobacco leaves. Six months later, he died.

Recently, in my garage, I found the bundle of leaves, perfectly preserved in a deep caramel sheen. I inhaled and could see my patient there in the clinic again — his operation, his strength, and his death, all from this gift from his life’s story.”

A. Scott Pearson, Surgeon, Author,  
and Associate Professor at Vanderbilt University



## PROVIDER | CAREGIVER | Listening

“When people experience traumatic news, they frequently go into a cognitive or emotional fibrillation (e.g., kinetic, repeated movement, thoughts, talking that is not productive). They can’t move forward to make smart choices — they’re stuck. By listening, staying mostly silent, and collecting the pieces of insight and information that emerge, together you can feel your way through strategic plans that they can grasp.”

Advice from a patient advocate

## PROVIDER | Listening

“On her fourth visit to the ER, a patient with emphysema tells her team of providers that she hasn’t been using the oxygen tank prescribed to her. The frustrated group of providers gather to discuss the reasons for her non-compliance: “She doesn’t care”, “She’s just too lazy”, “I bet she forgets since she seems so absent-minded”... They all assume that it’s the patient’s fault. At a loss for other possibilities, it occurs to the team that they should ask the patient. She explains to them that her mother had been on oxygen when she was a child. Something went wrong one night, and the oxygen caught fire, leading to the destruction of their home. Upon learning this, the team re-trains the woman for safe use of the oxygen and assures her it is safe. After this, there are no more emergency visits.”

Inspired by stories told to Laura Hope Gill,  
Director of Thomas Wolfe Center for Narrative at Lenoir-Rhyne University



## **PROVIDER** | Clinical Narrative

“A cardiac surgeon stands at the operating table with his team. The patient is prepped for a triple bypass. The tools glint in the bright lights. Before making the incision to expose the patient’s heart, he tells his team the patient’s name, that she is an Iraq veteran, a mother of three, and that she likes the BeeGees. The surgery begins. After the procedure is complete, his team tell him they wish every surgeon told a little story about the patient. They say it gave the surgery more meaning.”

Inspired by stories told to Laura Hope Gill,  
Director of Thomas Wolfe Center for Narrative at Lenoir-Rhyne University



## PROVIDER | Clinical Narrative

“I knew it was a long shot, it was midwinter and every A and E department in the country was groaning under the pressure. I’d seen ambulances backed up down the road as I’d run past the hospital earlier that morning. ‘Come on; answer your bleep, answer your bleep.’

I could imagine the Med Reg in the middle of the melee, barking orders, making decisions; quick decisions, not the decisions he wanted to make, decisions he was forced to make, pressure of time, pressure of space, pressure.

It was Saturday afternoon on the 20th of Dec 2014. I was wasting my time, he’d never accept her, and even if he did what would that mean for her? Would she be left for hours on a trolley? Left as dying, which of course she was.

Then a brisk voice cracked on the phone, ‘Dr Wilcox speaking.’

My mind froze for a second, the madness of my request hanging in front of me, my professional pride on the line, what was I doing?

‘Hello’ said the voice. Seconds counted, where he was standing.

...



'Hi, sorry to bother you, I know you must be so busy.' My voice sounded oddly calm as I began my pitch. 'I'm Dr Marshall-Andrews a GP at BHWC. I was wondering if you could see a 52-year-old lady for me; she has been vomiting off and on for over two weeks. She can barely keep anything down. Her children have gone to Dublin for 3 days before Christmas. She is badly dehydrated, her BP is 100/70 with a 10mmhg postural drop. Her pulse is 110. She is producing small amounts of dark urine. We are trying to get her a bit better for Christmas and so she may be able to start another round of chemo in a few weeks.'

I was going to have to say it, I couldn't leave out the key factor anymore. 'She has a malignant ovarian tumour with widespread peritoneal mets intermittently obstructing her bowel.'

There was a pause 'So she is palliative,' he said. I took a deep breath. 'Yes.'

'Well she can't come here, she needs to go to the Hospice.'

'She won't go to the Hospice,' I replied. Knowing it was over. I had failed her.

'Well she'll have to, she can't come here,' he repeated, preparing to leave the phone. I could almost hear the next sentence he would utter when the receiver went down: 'Idiot GP.'

...





'Wait, please let me just tell you about her.'

'She came over from Dublin with her best friend Angie 17 years ago to work in London. Angie had two children whose father left shortly after the younger daughter was born. When the children were 2 years and 4 years old Angie developed ovarian cancer and despite every effort she died in the Hospice here just before Christmas 10 years ago. Melanie adopted her children and has brought them up as her own. Three years ago she developed ovarian cancer and despite three cycles of chemotherapy it has spread to her liver and lung and wrapped around her bowel. She has not been able to face telling her children how bad she is just before Christmas. She won't go to the Hospice.'

There was a silence which felt like forever. Would he understand? How by the book was he? Would he bend the rules? In the exhaustion and stress had he lost his humanity?

'Send her up.' And with a click the line went dead.

'Thank you, thank you so much,' I whispered into the air."

Laura Marshall Andrews,  
Principal Medical Practitioner at Brighton Health and Wellbeing Center



## PATIENT | Expressive Arts

“Today a year ago my life was turned upside down  
Today a year ago I got the bad news  
Today a year ago I thought I was gonna die within a few years  
Today a year ago my mind went into shock  
Today, I actually had a lot of fun  
Today I celebrated my first-year anniversary  
Today the world looks completely different  
Today I am me again  
Today I actually cried tears of laughter and not of sadness

Yes, my life has been affected by HIV and if not treated, it's life-threatening. But I had time to get over it. My doctors have been taking fantastic care of me. I started my meds a few months ago even though I didn't need to yet, but I wanted to preserve my brains and guts. I made a lot of new friends and some of them have become really close. I have been on stage, which I never thought I would. I even had sex again — I felt like a virgin but I did it (-). I went through ups and downs as has everyone, but overall I have to say I made it another year and it was definitely not my worst and also not my last. So people, watch out — here I come again, better than ever.”

Reflections from HIV-positive woman participating in  
The Medea Project: HIV Circle, an expressive theater intervention  
Copyrighted by Cultural Odyssey and Rhodessa Jones 2010



## **CAREGIVER** | Expressive Arts | Storytelling with Purpose

“After suffering months of pain, a young husband and father is diagnosed with metastatic kidney cancer. His wife and family struggle to get him appropriate care during 11 weeks of continuous hospitalization at five different facilities. Frustrated and heartbroken, they turn to art as a way to make sure no one else has to go through what they did. The husband died, but the wife begins a series of public murals about their experience, and founds an advocacy movement by painting patient stories on the backs of business suit jackets. She calls it The Walking Gallery, where stories became the gateway to talking about patient rights. For her: “I paint because it’s the best way I know to make a difference. I will paint our sorrow on a wall for all to see. It’s hard to look away. It makes you think. It makes you question.”

Inspired by the story of Regina Holliday and her Walking Gallery



## PROVIDER | Expressive Arts

“We performed our play *Bedside Manners* at the University of California, San Francisco to 200 registered nurses in a patient safety program. Eleven nurses and four physicians volunteered to act as characters in the play, which focuses on teamwork in healthcare. The physician/actors were chosen very strategically in order to include a resident, an attending, as well as several other physicians who weren’t entirely convinced about the teamwork message. Nurses played doctors, doctors played nurses.

The play took 45 minutes to perform and was followed by a three-hour discussion between these doctors and nurses. They revealed they had never had such an intense and productive interprofessional conversation before. The play encouraged people to reveal problems they would never have discussed if they were presented with a lecture, PowerPoint, or even an anonymous survey. It got them in a storytelling mood and they discussed not only problems but many solutions.

You can lecture people for hours and get nowhere but tell the right story and suddenly there’s a miracle – “Oh finally I get it.” At least sometimes, which is just what we need.”

Suzanne Gordon, Healthcare Journalist, Editor and Patient Safety Advocate;  
Advocate for Use of Theatrical Techniques in Transforming Healthcare Culture



## PROVIDER | Expressive Arts

“I find the expressive arts a valuable method for students to represent the power of narrative. At Vanderbilt University, I teach a seminar using stories of illness. I ask each pre-medical student to journal about someone they have known with illness, often a family member, friend, or even themselves. Then, for the culmination of our course, I ask the students to represent their patient’s narrative with an art form of their choosing which they prepare and present to the class. At first skeptical, they often reclaim dormant talents. Some write a poem, or a song, or create a visual representation. Others collaborate in theatrical scenes to show their patient interacting with a provider. Emotions are released and it is not unusual to see tears as they honor those with illness. Of the spectrum of expressive arts displayed, one feature is constant: the student’s connection to the patient’s narrative—immediate, visceral, and lasting.”

A. Scott Pearson, Surgeon, Author, and  
Associate Professor at Vanderbilt University



## **PATIENT** | Journaling | Peer-to-Peer Sharing

“Through my work with individuals and families living with chronic illness and pain, I have often seen the power of writing used as an effective tool for resilience. As online writing in the form of blogs became more prevalent over the past decade, I became curious as to their benefit for connection and of telling one’s story in real time in the online space. In 2011, I, along with several of my Tufts University School of Medicine colleagues, embarked on a study of current illness bloggers to try to better understand their motivation for writing about their illnesses in this public way. What we discovered — the process of communicating the experience of chronic illness and pain through blogging seemed to provide benefit for many in moving toward a more complete, holistic model of health and healing by allowing to regain a place in the larger society. A quote from one of our study participants says it all — ‘First I was helped, now I am helping... a reminder that I am part of the world’.”

Pamela Ressler, Founder of Stress Resources and  
Faculty of Pain Research, Education and  
Policy Program at Tufts University School of Medicine



## **PATIENT** | Journaling | Peer-to-Peer Sharing

“First you may be helped but as you continue to share and connect you will shift from being the one who is helped to the one who is helping — a wonderful way to regain meaning and purpose in life. Consider exploring online peer to peer support communities or starting a blog to share your experience.”

Pamela Ressler, Founder of Stress Resources and  
Faculty of Pain Research, Education and  
Policy Program at Tufts University School of Medicine

## **PROVIDER** | Journaling | Personal Narrative

An E.R. nurse ends a 12-hour shift feeling as though he has witnessed a war. Patients have flown through the doors so quickly in such degrees of trauma that he has had to turn himself into a machine just in order to get all the vitals down and the patients admitted. As he walks out of the hospital, he looks up and sees a bright, full moon. Its edges blur. He realizes he is crying. He lowers himself into his car and drives home. Once there, even though he is exhausted, he does not go immediately to bed. He sits at his dining room table with a cup of tea and writes one short letter he will never send. It is to the patients he saw and will probably never see again. He engages in this practice at the end of every shift as a way of processing and coping with the heartbreak he experiences each day.

Inspired by stories told to Laura Hope Gill,  
Director of Thomas Wolfe Center for Narrative at Lenoir-Rhyne University



## PATIENT | CAREGIVER | Peer-to-Peer Sharing

“It took a child to help me understand the power of connection when one has a chronic illness. My son, Nick, was diagnosed with a rare form of cancer when he was 14 years old in 2000. We quickly became overwhelmed with the complexity of managing a life-limiting illness — hospital admissions and readmissions, surgeries, chemotherapy and radiation schedules, pain that could not be adequately managed even with the most potent analgesics. After one particularly difficult day, Nick turned to me and said “I just want to be a kid again” — in that instant I realized that through the diligent management of his disease we had all lost sight of the person, Nick, the teenager.

We found a way, in the early days of online chat, for Nick to be connected to his friends back home, through a borrowed laptop computer and a dial-up connection in his hospital room — he became a kid again, part of the world, sharing stories, homework, jokes, gossip, and typical teenage angst. Tragically, my son did not survive his illness, but he left me with profound gratitude for the lesson he taught me — we are much more than our diagnosis and through connecting with others and by sharing our stories, we can reclaim a bit of our citizenship in the world of the well.”

Pamela Ressler, Founder of Stress Resources and  
Faculty of Pain Research, Education and  
Policy Program at Tufts University School of Medicine





## **CAREGIVER** | Peer-to-Peer Sharing

“While the stories of caregivers are intertwined with those for whom they care, they have their own stories as well. Peer-to-peer communities serve to connect and share experiences of caregiving. Digital technology platforms allow caregivers to create a space in which to reflect and find some respite and renewal.”

Pamela Ressler, Founder of Stress Resources and  
Faculty of Pain Research, Education and  
Policy Program at Tufts University School of Medicine

## **PATIENT** | Individualized Learning | Personal Narrative

“At age 52, I had lived an incredibly normal life in terms of personal wellness. The words, “You have prostate cancer,” from my urologist pierced my commute with urgency and despair.

The gift of this health opportunity was not revealed fully for weeks, but it began that night when I sat in my 5-year old daughter’s Montessori classroom, silently experiencing the beauty of her typical day through my new lens.

...



Later, reading Laurence Gonzalez's book "Deep Survival: Who Lives, Who Dies and Why", I realized that I had been the recipient of one the key aspects of survivors: that when a life threatening incident occurs, the first step is to pause, take in the beauty of the situation, and then get to work.

That moment of silently taking in the space of possibilities of my daughter's school, was the moment I moved from being a victim to being an advocate."

Bill Hill, Founder of Experience Design, Inc.



## **PATIENT** | Individualized Learning | Personal Narrative

Paul Kalanthy, a Stanford neurosurgeon, was diagnosed with stage IV lung cancer at the age of 36. In navigating his uncertain future, the provider-turned-patient found comfort in seven words from writer Samuel Beckett, “I can’t go on. I’ll go on.” Those words gave him the strength to face his own mortality. They repeated in his head as he woke up each day: “I can’t go on.” And they repeated in his head as he continued his life — in his scrubs, heading to the operating room: “I’ll go on.” Paul Kalanthy passed away on March 9, 2015 — less than two years after his diagnosis.

As reported in the 2014 New York Times article,  
“How long have I got left?” by Paul Kalanthy



## **PATIENT** | Storytelling With Purpose

“After I finished treatment, I kept having this recurring daydream. I was floating over my own funeral, listening to people talk about how I’d lived so long considering all the cancer in my liver, what a fighter I was; what a testament it was to how much I loved my kids. I remember wanting to scream: ‘No! I didn’t have to die! I could have lived! I didn’t have dozens of tumors in my liver, only one!’

When you’re diagnosed, you feel like the healthcare system is trying to find a way to get you on the moving walkway, progressing toward treatment. When you try to take time to learn about all the options, and make a decision based on your own values, you’re off the moving walkway, not complying with the plan that’s been presented, not checking a box. Keeping track of you, as you take the time YOU need, requires them to adapt to your timing, your process. And that’s not efficient or profitable for the system which wants, above all, for you to get in the system, on the walkway.

...



I was blessed with survival, and with the chance to create something that gives meaning to an experience that changed my life, to seek to ease the burden for others. At the Center for Patient Partnerships, we train future doctors, nurses, pharmacists, lawyers – anyone who interacts with patients – to decrease the burden of suffering, not to add to it by how they approach people who are sick and frightened. They must insist on humanity, theirs and ours. My work is a profound gift.”

Meg Gaines, Associate Dean at University of Wisconsin Law School,  
on the impetus for developing the Center for Patient Partnerships



## **PATIENT** | Storytelling With Purpose

“At my first advisory committee meeting as an voting patient representative to the U.S. Food and Drug Administration, physicians on the panel stated strongly that patients with the relevant condition for the medication under review died, indicating and that there would be little benefit. Having had this condition 18 years prior, when it was my turn to speak, my patient narrative was simply, ‘Some of us live, and we’d like the best chance possible to do that.’ The committee voted to approve.”

Donna Cryer, President & CEO of the Global Liver Institute



## PROVIDER | CAREGIVER | Storytelling With Purpose | Personal Narrative

“I used to work with Planetree, a leading pioneer in patient-centered care, and we would hold staff information sessions at new member hospitals. I would ask everyone in the auditorium to tell me who considered themselves caregivers? Typically, the nurses, physical therapists, pharmacists, and other clinical personnel would raise their hands. One day, I asked my question and the hand of a fellow in an engineering uniform shot up. I called on him and invited him to tell us why he considered himself a caregiver. He said, ‘I am a licensed electrician and when I’m down in the sub-basement working on a power panel that serves the critical care unit, I am a caregiver, I am ensuring the safety and well-being of patients, families, and other hospital staff. It gives me great pride to do my job and to think about the impact I am having; that’s why I’m a caregiver.’ I think his story, that day, inspired and empowered others who had never done so before to think of themselves as caregivers.”

Paul Stillman, PhD, Senior Consultant, Vital Signs  
at Six Seconds, The Emotional Intelligence Network



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Theresa Brown



Maggi Cary, MD



Donna Cryer, JD



Valerie Flower



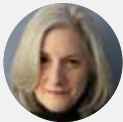
Meg Gaines



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Kristen M. Gurdin



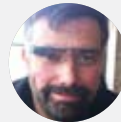
Bill Hill



Regina Holliday



Laura Hope-Gill



Bill Kelly



Bruce Kelly, MD



Sarah Kucharski



Arno K. Kumagai



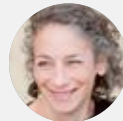
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### **ABOUT THE BUSINESS INNOVATION FACTORY**

At the Business Innovation Factory, we help leaders design and test transformational business models. We do this in complex social systems like healthcare, education, and government, where there is the highest potential and impact for making people's lives better is the highest. Our approach is human-centered, seeking to understand the jobs customers need done, and using these insights to design new experiences that will better serve them. We experiment in the real world, and rely on storytelling to engage others in the process.

[www.businessinnovationfactory.com](http://www.businessinnovationfactory.com)

### **ABOUT THE ROBERT WOOD JOHNSON FOUNDATION**

For more than 40 years the Robert Wood Johnson Foundation has worked to improve the health and health care of all Americans. We are striving to build a national Culture of Health that will enable all to live longer, healthier lives now and for generations to come.

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# ADDITIONAL RESOURCES





# NARRATIVE RESOURCES

## Recommended Reading List: Narrative in Healthcare

- Belle., J., et al. (2012). Challenges and Solutions: Narratives of patient-centered care (patient-centered care series).
- Bolton, G.E.J. (2010). Reflective Practice: Writing and Professional Development.
- Charon, R. (2006). Narrative medicine: Honoring the stories of illness.
- DeSalvo, L. (1999). Writing as a way of healing: How telling our stories transforms our lives.
- Engel, J., et al. (2012). Developing Clinicians' Career Pathways in Narrative and Relationship-Centered Care: Footprints of Clinician Pioneers.
- Frank, A. (1991). At the will of the body: Reflections on illness.
- Frank, A. (1995). The wounded storyteller: Body, illness, and ethics.
- Greenhalgh, T. & Hurwitz, B. (1998). Narrative Based Medicine.
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- Kane, J. (2013). The bedside manifesto: healing the heart of healthcare.
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- Launer, J. (2012). Narrative-based Primary Care: A practical guide.
- Lepore, S. (2002). The writing cure: How expressive writing promotes health and emotional well-being.
- Lown, B. (1999). The Lost Art of Healing: Practicing compassion in medicine.
- Meza, J.P., et al. (2011). Integrating Narrative Medicine and Evidence Based Medicine: The everyday social practice of healing.
- Pennebaker, J. (1997). Opening up: The healing power of expressing emotions.
- Sanders, L. (2009). Every patient tells a story: Medical mysteries and the art of diagnosis.
- Silverman, J., et al. (2013). Skills for communicating with patients.
- Squire, C., et al. (2014) What is narrative research?
- Sweet, V. (2013). God's Hotel: A doctor, a hospital, and a pilgrimage to the heart of medicine.
- Wen, L., & Kosowsky, J. (2014). When doctors don't listen: How to avoid misdiagnoses and unnecessary tests.





## PERSONAL NARRATIVE

### Online Compilations of Patient Stories

There are many website that collect stories of patients.  
Here are just a few:

- PatientStories: [www.patientstories.org.uk](http://www.patientstories.org.uk)
- Back in the Game: [www.backinthegame.hss.edu](http://www.backinthegame.hss.edu)
- Experts By Experience Patient Stories: [bit.ly/19nltLz](http://bit.ly/19nltLz)
- CancerForward Survivor Stories: [bit.ly/1CRzu0h](http://bit.ly/1CRzu0h)
- Pulse – Voices from the Heart of Medicine: [www.pulsevoices.org](http://www.pulsevoices.org)

### Online Compilations of Caregiver Stories

There are many website that collect stories of patients.  
Here are just a few:

- Caring.com: [bit.ly/1EH193I](http://bit.ly/1EH193I)
- Family Caregiver Alliance: [bit.ly/1OAE8EJ](http://bit.ly/1OAE8EJ)
- Alzheimer’s Association: [bit.ly/1BsSEW3](http://bit.ly/1BsSEW3)



## LISTENING

### Listening Training Programs:

- Columbia University – Narrative Medicine Program: [ce.columbia.edu/narrative-medicine](http://ce.columbia.edu/narrative-medicine)
- Lenoir Rhyne University – Thomas Wolfe Center for Narrative: [www.lr.edu/academics/programs/writing/program](http://www.lr.edu/academics/programs/writing/program)
- Institute for the Study of Health & Illness (ISHI): [www.ishiprograms.org/programs](http://www.ishiprograms.org/programs)





## CLINICAL NARRATIVE

### Software, apps, and tools for augmenting Electronic Medical Records with narrative:

- ReelDx: [www.reeldx.com](http://www.reeldx.com) (create and share Personal Clinical Videos)
- OpenNotes: [www.myopennotes.org/](http://www.myopennotes.org/) (National initiative working to give patients access to the visit notes written by their doctors, nurses, or other clinicians)
- Twistle: [www.twistle.com](http://www.twistle.com) (Collaborative Electronic Health Records platform)
- HIPAA-chat: [www.hipaachat.com](http://www.hipaachat.com) (HIPAA compliant text messaging and telemedicine)
- CaptureProof: [www.captureproof.com](http://www.captureproof.com) (Secure communication between patients & providers)



## EXPRESSIVE ARTS

### Writing Workshops

Your best bet is to check local colleges and universities as well as local writers' associations. Writer's Digest also lists writing workshops & offers an online workshops ([www.writersdigest.com](http://www.writersdigest.com)).

### Theater Workshops

Like writing workshops, check out local theater groups. In particular, see if there are workshops for Theater of the Oppressed, Participatory Theater or Forum Theater.

### Art Workshops

See if there are creative arts or expressive arts workshops in your area, either through a healthcare organization, universities, or local practitioners.

Here are a few places to start:

- Americans for the Arts: [www.americansforthearts.org](http://www.americansforthearts.org)
- Finding Your Compass: [www.findingyourcompass.co.uk](http://www.findingyourcompass.co.uk) || [vimeo.com/93264018](https://vimeo.com/93264018)
- Outside In: [www.outsidein.org.uk](http://www.outsidein.org.uk)
- Disability Arts Online: [www.disabilityartsonline.co.uk](http://www.disabilityartsonline.co.uk)

### Theater Resources

- Boal, A. (1979) Theatre of the Oppressed.
- Boal, A. (1992), Games for Actors and Non-Actors.
- Boal, A. (1995) Rainbow of Desire.
- Cohen-Cruz, J. (2010) Engaging Performance: Theater as Call and Response.
- Landy, R. L. & Montgomery, D. T. (2012). Theatre for Change: Education, Social Action and Therapy.
- Moreno, J.L. (1946/1994), Psychodrama.
- Needlands, J. and Goode, T., Structuring Drama Work: A Handbook of Available Forums in the Theatre and Drama.
- Nicholson, Helen (2005) Applied Drama.
- Schutzman, M. & Cohen-Cruz, J. (1994) Playing Boal- Theatre, Therapy and Activism.
- Spolin, V., (1999) Improvisation for Theater.
- Journal of Applied Arts and Health: <http://www.intellectbooks.co.uk/journals/view-Journal,id=169/>
- International Expressive Arts Therapy Association: <http://www.ieata.org/>

### Specifically for work with children

- Bolton, G.M. & Heathcote, D., (1999) So You Want to Use Role-play? A New Approach in How to Plan.
- Booth, D. (2005) Story Drama: Creaqting Stories through Role-playing, Improvising and Reading Aloud.
- Mc Caslin, N. (1999) Children and Drama.
- McCaslin, N. (2006) Creative Drama in the Classroom and Beyond.
- O'Neill, C & Lambert, A., Drama Structures: A Practical Handbook for Teachers.





## PEER-TO-PEER SHARING

### Recommended Blog List

- Sarah Kucharski:  
[afternoonapsociety.blogspot.com](http://afternoonapsociety.blogspot.com)
- Lisa Bonchek Adams: [www.lisabadams.com](http://www.lisabadams.com)
- Nancy Stordahl: [www.nancyspoint.com](http://www.nancyspoint.com)

### Support Groups

For patients/caregivers:

- HealthFinder: [healthfinder.gov](http://healthfinder.gov)
- Mental Health America: [bit.ly/1HNmHLL](http://bit.ly/1HNmHLL)
- Local Meetups: [www.meetup.com](http://www.meetup.com)

### Patient-Specific Online Communities

- Patients Like Me: [www.patientslikeme.com](http://www.patientslikeme.com)
- Dipex: [www.dipexinternational.org](http://www.dipexinternational.org)
- Twitter: [www.twitter.com](http://www.twitter.com)
- Facebook: [www.facebook.com](http://www.facebook.com)

### Caregiver-Specific Online Communities

- CaringBridge: [www.caringbridge.org](http://www.caringbridge.org)
- Care Giving: [www.caregiving.com](http://www.caregiving.com)
- Caring Road: [www.caringroad.com](http://www.caringroad.com)
- Inspire: [www.inspire.com](http://www.inspire.com)
- Twitter: [www.twitter.com](http://www.twitter.com)
- Facebook: [www.facebook.com](http://www.facebook.com)

### Provider-Specific Online Communities

- Doximity: [www.doximity.com](http://www.doximity.com)
- Sermo: [www.sermo.com](http://www.sermo.com)
- Doc2Doc: [www.doc2doc.bmj.com](http://www.doc2doc.bmj.com)
- Mighty Nurse: [www.mightynurse.com](http://www.mightynurse.com)
- allnurses: [www.allnurses.com](http://www.allnurses.com)
- Just Us Nurses: [www.justusnurses.com](http://www.justusnurses.com)
- Twitter: [www.twitter.com](http://www.twitter.com)
- Facebook: [www.facebook.com](http://www.facebook.com)





## INDIVIDUALIZED LEARNING

### Patient Resources

- Kelly, A. (2014). The predatory lies of anorexia: A survivor's story.
- Alexander, R., & Alper, S. (2014). Not fade away: A memoir of senses lost and found
- Biro, D. (2001). One hundred days: My unexpected journey from doctor to patient.
- Cahalan, S. (2012). Brain on fire: My month of madness.
- Lucas, G. (2005). Why I wore lipstick to my mastectomy.
- Price, R. (1994). A whole new life.
- Hoffman, L. (2014). Radiation days: The rollicking, lighthearted story of a man and his cancer.
- Bellevue Literary Review: [blr.med.nyu.edu](http://blr.med.nyu.edu)
- For a list of illness-specific narratives: [bit.ly/19OrloJ](http://bit.ly/19OrloJ)

### Caregiver Resources

- Comer, M. (2014). Slow dancing with a stranger: Lost and found in the age of Alzheimer's.
- Bellevue Literary Review: [blr.med.nyu.edu](http://blr.med.nyu.edu)
- For a list of illness-specific narratives: [bit.ly/19OrloJ](http://bit.ly/19OrloJ)

### Films and Plays

- Wit (play, 1999; film, 2001, starring Emma Thompson)
- The Doctor (1991, starring William Hurt)
- Bedside Manners (play and workbook by Suzanne Gordon, Lisa Hayes & Scott Reeves)
- Sick (Play by Elizabeth Kenny)
- Next to Normal (Musical by Brian Yorkey)
- Vagina Monologues (play written by Eve Ensler)
- Ruined (play by Lynn Nottage)

### Provider Resources

- Biro, D. (2001). One hundred days: My unexpected journey from doctor to patient.
- Brown, T. (2010). Critical care: A new nurse faces death, life, and everything in between.
- Ofri, D. (2009). Medicine in translation: journeys with my patients.
- Ofri, D. (2013). What doctors feel: How emotions affect the practice of medicine.
- Transue, E. (2005). On Call: A Doctor's Days and Nights in Residency.
- Watts, D. (2005). Bedside Manners: One Doctor's Reflections on the Oddly Intimate Encounters Between Patient and Healer.
- Bellevue Literary Review: [blr.med.nyu.edu](http://blr.med.nyu.edu)



## STORYTELLING WITH PURPOSE

- Patient Advocate: [www.patientadvocate.org](http://www.patientadvocate.org)
- Patient Voice Institute: [www.patientvoiceinstitute.org](http://www.patientvoiceinstitute.org)
- National Speakers Association: [www.nsaspeaker.org](http://www.nsaspeaker.org)
- StoryCorp: [www.storycorps.org](http://www.storycorps.org)
- Positive Women's Network: [www.pwnusa.wordpress.com](http://www.pwnusa.wordpress.com)
- The Walking Gallery: [www.reginaholiday.blogspot.com/2011/04/walking-gallery.html](http://www.reginaholiday.blogspot.com/2011/04/walking-gallery.html)
- Rare Disease Storytelling Toolkit: [bit.ly/19UhUhi](http://bit.ly/19UhUhi)
- Patient Passport: [www.doctella.com](http://www.doctella.com)



### Additional resources from our collaborators

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