

The background of the slide is a dark blue, semi-transparent overlay over a photograph of a person's hands typing on a laptop keyboard. The person is wearing a light-colored, long-sleeved shirt. To the left of the laptop, a white coffee cup sits on a matching saucer. The overall scene is dimly lit, with the primary light source being the laptop screen, which is not clearly visible.

# TELLING YOUR PERSONAL STORY: A How-To Guide

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# INTRODUCTION

You already know how important your personal story is to your advocacy. In a face-to-face meeting or in written communication with a decision maker, your personal story makes your issue come to life. It makes your issue real for the decision maker and provides a point of connection between the two of you. Your personal story fuels the logic of your one “ask.” You know it needs to be emotional and motivating, clear and concise.

- But how exactly should you go about writing and telling your personal story?
- Where do you start? Where do you stop?
- How do you know if your story is impactful?
- How should you present your story to the decision maker?

## Goals and Organization of this Guide

This guide aims to answer these questions. It provides concrete strategies for writing and telling your personal story, the foundation of any advocacy effort. The guide is intended for patients, families, caregivers, and other individuals who want to create a personal story to support a specific health care intervention. We focus here on telling a condensed, five-minute version of your personal story for your meeting or written communication with a decision maker (e.g., your provincially elected representative). In many ways, constructing a five-minute story is more difficult than telling your entire story. After all, your five-minute story needs to compel your decision maker to act on your one “ask” just as your longer story would, but without the context your longer story can provide. This guide will walk you through how to construct, revise, and present your five-minute personal story.

We start with a brief review of what constitutes a personal story and the essential elements of a personal story. From there, we move to “Getting Started”; and we start writing by writing. This chapter provides concrete tools and exercises to get you started on writing your story. It answers the question, “How do I start?” Chapter 2 helps you find an appropriate structure for your story. It also addresses the two most common problems of writing: what to do when you’re stuck and what to do when you find yourself with too much material. Chapter 3 provides a few suggestions for preparing to tell your story, practising your delivery, and delivering your story during the meeting. Finally, we conclude with a checklist of items that you can use to verify the effectiveness of your story and your preparedness for your meeting.

## What Is a Personal Story?

- Your personal story is a summary of what has happened to you as it relates to the issue at hand.
- It is your perspective on the issue based on your experience, feelings, and attitudes.
- It is emotional.
- It must demonstrate how government action/inaction/policy/etc. has directly impacted your life.

## Essential Elements of Your Personal Story

This is an outline of the essential elements of your personal story. We'll revisit this outline in Chapter 2 when we discuss the structure of your story.

### 1. Basic personal details

- Your name, age, where you live
- Your occupation (or former occupation)
- Details about your family (e.g., married x years, x children, etc.)

### 2. Facts about your personal situation

- For example: your diagnosis, the timing and circumstances surrounding your diagnosis (or the diagnosis of your loved-one)
- Convey how you felt and/or continue to feel

### 3. The issue

- Clearly define the issue (e.g., access to medication, finding the right physician, problematic policy or legislation, etc.)
- Aim to answer the question, why is this issue important?
- For example: the challenges you face or have faced as a result of the disease, particularly related to the relevant issue for which you are advocating

### 4. Action (your one “ask”)

- What do you want done?
- Tell the decision maker what you believe government (or other organization/person) needs to do to help you and others

At every point, convey your feelings about the details or events you're describing, as well as suggestions or solutions to achieve one “ask” you're making.



# CHAPTER 1

## Getting Started: Starting to Write by Writing

### How Do I Start? Where Do I Start?

For experienced and inexperienced writers alike, starting is the hardest part. The blank page, the blank screen, they just stare back at you ... blankly. So, how do you start? To put it simply, you start writing by starting to write. This section provides some starting strategies and prompts for you as you begin to construct your personal story. Try one strategy or try them all. We suggest you read through them first to see if there's one that strikes you as particularly interesting. If there is, start with that strategy. Hopefully, you'll only need one strategy to get started, but there's no shame in trying them all out or in building your own strategy from the recommendations here. Just start writing by writing!

#### **Before we talk specific strategies for starting to write, consider the following advice.**

1. Do not aim for a polished story right away. These “getting started” strategies are about letting your mind wander through possible versions of your story. That means that you don't even need to start at the beginning. You can start anywhere.
2. Do not worry about correct spelling, punctuation, or grammar at this stage.
3. It's good to keep in mind that you'll be sharing your story with a decision maker eventually, but when you're getting started, write for yourself. Write to learn what you're thinking and what you deem most important about your story.

## STRATEGY 1



## Freewriting

Get a piece of paper and a pen or put your hands on the keyboard and just start writing. Forget about the rules for a while. Don't worry about spelling or grammar or punctuation. If you can't think of the right word, write something close to it, or leave a blank space and move on. Freewriting is writing to discover what you're thinking, what you have to say, and, in this case, what you want to tell others about your issue, your life, and your aspirations and needs as they relate to your issue.

You can write as long as you'd like, but if the idea of writing for an unlimited time freaks you out, set a timer for 15 or 20 minutes. Commit to keeping your pen or your fingers moving for that amount of time. Even when you reach what appears to be a dead end, simply move on, or start again someplace else. Just keep writing.

It might seem like you have a page (or two or three) of gibberish at the end of your freewriting session but, most likely, there's a thread in there that you'll want to pursue. If you're not sure about it or you're feeling like you haven't made too much progress with the freewriting, set it aside; come back to it tomorrow.

When you read it with fresh eyes, look for:

- ideas or sentiments that you've repeated. It's likely that those things are what's most important to you and, in turn, what might be most important to others.
- descriptions, ideas, feelings, etc. that surprise you. Are you surprised because something you've written is a powerful idea or description? If so, you know it's a keeper – something you'll want to incorporate into your story.
- connections between ideas, events, and experiences you may not have thought about before. Are these connections helpful for thinking about how to organize your story?

With any luck, you might also notice possible ways to focus and organize your story. For example, perhaps you wrote about three events that led to your diagnosis, but, as you read through your freewriting, you realize you wrote one sentence about two of them and a half a page about the third event; it's likely that the third event is central to your story. Perhaps, then, that event becomes your focus.

## STRATEGY 2



## Listing

Listing is a way to discover ideas or to pin them down by writing. Like freewriting, listing can help if you're not convinced that you have something to say. The process is sort of like making a shopping list: you write down "laundry soap," for example, and you suddenly remember that you have to pick up the dry cleaning. Or, to use another example, you write down "eggs" and remember that there's leftover bacon in the fridge (which you will then likely eat immediately). On a more serious note, if you plan to advocate for a course of action (which you do in your one "ask"), listing one reason for it may bring others to mind.

Listing might also help you find a focus for your five-minute personal story. You might start by listing all the challenges you've faced since your diagnosis, for example, and in that list you might discover one that stands out as most relevant to your issue or most powerfully supports your one "ask."

Other examples of things you might list to get started:

- The biggest surprises (pleasant or unpleasant) of your experience living with your condition (or that your loved-one has experienced)
- What people most often say to you when you tell them about your diagnosis or condition
- How your closest friends and family have been affected by your condition
- The most helpful things people have done so far in response to your diagnosis or condition
- The most helpful things people could do in response to your diagnosis or condition
- The impacts on your life of government action/inaction/policy etc. related to your condition

As you make your list(s), you'll probably find that you have a lot more to say on two or three items than on the others. Let the lists be your guide. You might make another list on just the two or three items that have emerged as a possible focus. You're much closer now to knowing what specifically you want to include in your personal story.



## STRATEGY 3



## Using Photographs

Photographs can be great storytelling tools. If you tend to enjoy visual storytelling (e.g., movies, TV, online videos, photography, plays) more than writing, perhaps this “getting started” strategy will suit you. Pick a few photos (*probably no more than five – otherwise, you’ll end up with way too much material*) that you deem relevant to the personal story you want to tell the decision maker. If you like, you can invite a friend or family member to help you choose the photos. He or she might also help jog memories associated with the photos. Photos can be of yourself or others or of anything, really – whatever you think is significant to your personal story. But, because photos can take you down memory lane fast and faraway from the task at hand, be sure to choose photos that represent events, places, people, experiences, etc. that are directly related to the essential elements of your story.

Explain why each photo is significant. What was happening to you at the time the photo was taken? How did you feel? If there are others in the photos, how did they feel? Are there connections between the photos? What do these photos represent to you? What do they say about your diagnosis, the challenges you face, the changes that have occurred or might occur in your life?

Write as much or as little as you like about each photo. Like freewriting, don’t worry about grammar, spelling, or punctuation. The idea here is just to get your ideas flowing.





You're probably familiar with the journalist's fundamental questions:

- **who?**
- **what?**
- **when?**
- **where?**
- **why?**
- **how?**

Just as journalists ask questions that are appropriate to their task (to report what happened, who made it happen, how it happened, etc.), so too can you formulate questions that will help you get to your story. Of course, you also need to answer the questions you pose. Think of it as interviewing yourself for a story.

You might consider the following questions:

- When, where, and by whom was your diagnosis made (or the diagnosis of your loved-one)?
- What challenges have you faced as a result of the disease? When and where have they occurred?
- How have you overcome or managed these challenges?
- What does the government (or other decision maker) need to do to help you and others?
- How would you be helped by this action(s)? How would others be helped?
- Why is inaction not an option?

## Next Steps

One or some or all of these four strategies will help you get over that hardest hurdle of getting started. Now you've got words on paper (or on a screen)! You'll begin to find threads that you'll want to pursue. You'll recognize significant details and events, and you'll likely gain a better understanding of what's most important to tell a decision maker. Now is the time to start writing more formally, using complete sentences and proper grammar, spelling, and punctuation. (But don't get hung up on grammar, spelling, and punctuation. **Above all, you need the story to be clear, coherent, compelling, and focused.** After all, the decision maker is not grading you on spelling if you're talking to him or her.) In the next chapter, we return to the essential elements of your personal story and discuss how to organize your story. We also address the two most common problems of writing: getting stuck and having too much material.



## CHAPTER 2

### Organizing and Revising

#### Now What? Finding a Structure?

Because your personal story needs to be *very focused* (after all, you only have five minutes to tell your story) and because *you have to conclude with why things need to change and bridge to your one “ask,”* your story must have a clear and logical structure that leads to that one “ask.” The outline of the Essential Elements of Your Personal Story not only guides the content of the story, it also provides a template for organizing your story.

As a general guideline, your story should be about 4 to 6 paragraphs. Remember that each paragraph should contain one central idea. In this version of the outline, we've included details about paragraph length and some further suggestions about organization.

#### Your Personal Story: An Outline

##### 1. Basic personal details (1 paragraph)

- Your name, age, where you live
- Your occupation (or former occupation)
- Details about your family (e.g., married x years, x children, etc.)

» Use the word “I” to tell your story. It’s about you, after all.

##### 2. Facts about your personal situation (1-2 paragraphs)

- For example: your diagnosis, the timing and circumstances surrounding your diagnosis (or the diagnosis of your loved-one)
- Convey how you felt and/or continue to feel

» This paragraph is where you’ll be able to firmly grab your listener’s attention. This is the part of the story where things change for you and you are faced with a new reality. Like a television show or any other kind of story, this part of your story introduces a tension that needs to be resolved and fuels the rest of your story.

### 3. The issue (2 – 3 paragraphs)

- Clearly define the issue (e.g., access to medication, finding a physician, problematic policy or legislation, etc.)
- Aim to answer the question, why is this issue important?
- For example: the challenges you face or have faced as a result of the disease, particularly related to the relevant issue for which you are advocating

» You might take 1 paragraph to define the issue and indicate why it's important, and another 1 or 2 paragraphs to explain the challenges you have faced.

» Again, if we think in terms of a TV show, this is the part of the story where we see what happens to the characters (in this case, real-life you) because of the tension that was introduced at the beginning of the story.

» For example, perhaps you have not been able to keep your job because the side effects of the current treatment you require have been difficult for you. Perhaps you take one paragraph to describe those side effects, how they affected your performance at work, and the implications of having to leave your job. This will lead you to your one "ask": funding for a specific medication that does not have such detrimental side effects and would enable you to go back to work.

### 4. Action (your one "ask") (1 paragraph)

- What do you need done?
- Tell the decision maker what the government (or other organization/person) needs to do to help you and others

» This paragraph is your conclusion and the bridge between your personal experiences and story and your one "ask."

» Make the connection between your story and your one "ask" clear. Be direct. Here's an example: "My story illustrates the importance of funding X drug. Having publicly funded access to this medication means that I will be able to re-enter the workforce and adequately support my family."

» Your one "ask" should be as succinct as possible. Practice writing it one sentence of 25 words or less. Again, be direct. Use the phrase, "I am asking you to..."

This outline is flexible enough to accommodate your unique, individual story but definitive enough to help you avoid writing too, too much. Still, you might experience some challenges as you write, the most common of which are at opposite ends of the spectrum: you're stuck or you have too much material. We discuss what to do in either case next.

## I'm Stuck! Overcoming Writer's Block

### 1. Take a break.

Take a nap. Have a snack. Go for a walk. Have coffee with a friend. Watch a movie. Do something other than sitting there with your pen poised over paper. A change of scenery often helps. If you can afford to take an entire day away from writing, do. When you come back to what you've written with fresh eyes, you'll likely be surprised by how much you already have to work with. Sometimes, a break is all you need to cure writer's block.

### 2. Try a “getting started” strategy that you haven't used.

Try a “getting started” strategy that you haven't used. Remember, you don't need to worry about finding the perfect words or grammar and spelling at this point. Just write.

### 3. Talk it out.

Tell your story to a friend or explain to them where you're stuck in your story. Be sure to have a pen handy. You'll likely find yourself telling your friend things that you'll want to include in your story. Voilà! Writer's block solved!

## Now I've Got Too Much Material: Paring it Down to Five Minutes

We can't emphasize this enough: Your story needs to be focused. All the details and descriptions need to illustrate your issue and lead to your one "ask." Making sure your story is always on-topic and relevant can be a challenge, even when you've only got five minutes to tell your story. Read your story aloud and time yourself. This will help you determine how much time (and material) you need to cut.

So, what if you have too much material? Try the following strategies to help pare your story down to five minutes.

**1.** Advice for overcoming writer's block works here too – take some time away from the story. When you approach it with fresh eyes, you might immediately see what works best and what material is less relevant and less compelling.

**2.** Revisit the Essential Elements for Your Personal Story. What elements have you added to your story that aren't on the essential element outline? Ask yourself:

- Is everything I have in my story *really* necessary?
- Have I repeated anything? (Eliminate the repetition.)
- Is the story focused on the issue?
- What details are not related to the issue? (Eliminate them.)
- What details do not help lead to my one "ask"?
- Could I use fewer words to describe a specific experience?
- Do these descriptions, sentiments, or ideas really support my one "ask"?
- Is my one "ask" as succinct as possible? Did I stick to one sentence or 25 words or less?
- What's the least interesting, relevant, or engaging part of my story as it stands? (Cut those elements.)

**3.** Have a trusted friend or family member read your story and ask their advice about what might be cut from the story. Ask them to consider the questions we've posed above.

Keep a separate file of the material you cut. After all, you might have occasion to tell a longer version of your personal story some day and this deleted material could come in handy!



## CHAPTER 3

### Preparing and Practising Your Delivery

You're nearly ready! You've got over writer's block, you've cut what needed to be cut. Your story is five minutes long, and it makes a compelling case for your one "ask." You're satisfied with what you've written and you're preparing for your meeting with a decision maker. What's the most effective way to prepare to tell your story? And what's the most effective way to tell the story? This chapter provides a few suggestions for preparing to tell your story, practising your delivery, and delivering your story during the meeting.

### Rehearsal and Reading

#### 1. Read your story out loud.

It may feel strange at first, but the best way to prepare to tell your story to a decision maker is to read your story out loud, alone or to a friend or family member. Perhaps practise reading alone first and then invite a friend or family member to listen to your story. Reading for an audience of even one friendly face can help alleviate any nervousness you might have about telling your story to a stranger.

Ask your friend or family member to let you know if you're reading too fast. We tend to read too fast rather than too slow when we're nervous; practising will help regulate your pace and calm your nerves.

As you read, watch for spots in your story where you tend to ad lib – that is, where you improvise and add material that isn't written in your story. Resist this urge to improvise and add to your written story. You need to stay focused on telling your story as you've prepared it.

#### 2. Time yourself.

When you're rehearsing your story, time yourself, or have your friend or family time you. Stick to your five minutes. But don't rush through your story to keep to your time limit. If you find you're way over time, you'll need to make some revisions. If you're significantly under five minutes, you'll need to make some additions.



### **3. You don't need to memorize your story. Your delivery doesn't need to be perfect.**

In fact, we suggest that *you read your story to the decision maker during the meeting*. This may seem like a strange suggestion because it goes against all public speaking tips, but consider the scenario. If you're a decision maker and you're having a conversation with someone and that person takes out a piece of a paper and says something like, "I would like to read you a short piece about my life as it relates to the issue we're discussing today," wouldn't that gesture get your attention? Taking the time to carefully read your story, rather than just work it into the conversation, signals to the decision maker that this is something you've put time, effort, and careful thought into – and that he or she should listen to you! Yes, reading your story does interrupt the conversational flow of the meeting, but that's exactly the point. That's part of what will make your story memorable and convincing.

And because you've been reading your story out loud as practice, you'll know where to emphasize certain phrases or pause for effect as you read your story to the decision maker.

### **4. Stay focused on telling your story.**

As you prepare to present your story to the decision maker, stay focused on telling your story – and sticking to your script – as you will want to do when you're actually face to face with the decision maker. The decision maker may interrupt you or ask a question during your story; of course, you don't want to be rude by not responding immediately, but it is alright to respond by saying something like, "That's a good question. I'll just finish reading you what I've written here, and then I'll answer it."

If you've enlisted a friend to help you practise telling your story, you might ask him or her to interrupt you so can rehearse this scenario. That way, you'll feel confident about how you might handle a situation like this when you go into your meeting.

# CONCLUDING CHECKLIST ✓

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Congratulations, you're almost ready to tell your story to a decision maker! Before you head off to your meeting or print the final copy, let's go through this checklist to make sure your story is as impactful as possible and that you are well prepared to deliver it.

Have you:

- verified that all the **essential elements** of a personal story are included in your story?
  - basic personal details
  - facts about your personal situation
  - the issue
  - action (your one “ask”)
- consulted the outline we have provided in “**Your Personal Story: An Outline**”?
- checked your organizational structure against the **provided outline**?
  - Do your paragraphs match the suggested organization?
- verified that your **one “ask”** is worded as directly and succinctly as possible?
- read your story aloud (more than once)?
- timed your story as you read aloud?
- edited as necessary to reduce repetition or unnecessary details? (See questions for revision in “Paring it Down to Five Minutes.” **Click here.**)
- timed your story *again* as you read it aloud to *verify you are within five minutes*?
- practised in front of a friend or family member?
- printed your story in a legible font for your meeting?

Have you ticked all the boxes? Great! Hopefully, you feel confident, prepared, and optimistic. Your story is the foundation of your advocacy, and you have the power to affect the change you need. You're well on your way! Good luck!



Be heard.

**We hope this How-To Guide  
helped you to BeHeard™!**

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