

# Share Your Rare Journey

If you or a loved one are living with a rare disease, choosing to tell your story is one of the most **powerful ways to advocate** for yourself. Sharing your personal story can be **impactful**, help to make an **emotional connection** with others, teach those listening new information and **educate others** on what they can do to help.

## Where do you begin?

Whether you're introducing your child to a new school, meeting your representative on Capitol Hill, or telling your new college roommate about your condition, below are some things to think about when crafting and sharing your story.

### Join the conversation.

Many people, including other patients, caregivers, industry, patient groups, media, doctors, researchers, and policymakers are helping to advance medicine and science. But in order for the rare disease puzzle to be complete, it needs to include all voices – including yours!

### Outline your goals.

What do you want people to do? Decide why you're telling your story – is it to help someone understand your needs, raise money, or change laws or the direction of research? Pinpoint what you want to accomplish, so that you can effectively inspire and motivate your listeners.

### Understand your audience.

Before preparing your story, it helps to know your audience. Who are you talking to? Think about their perspective, what questions they might have, what they need to know, and tell them what they can do to help.

### Remember your key messages.

Once you've determined the audience, it's time to decide what to say. Before you start, it's helpful to write down key points to deliver. Aim for 3 to 5 specific messages, with no more than 1 to 3 sentences each.

### Nail down your elevator speech.

An elevator speech should be as short as the time it takes to ride in an elevator (about 60 to 90 seconds). Try starting with "I am here today because ..." or "Did you know that ...?" Introduce yourself, describe your condition and its impact and preview what you want your audience to do.

### Elevate your confidence.

Practice your elevator speech with a friend or family member, or use your phone to record yourself. Ask the following questions:

- How did it sound? Interesting? Boring?
- Did you keep it short and clear, without extra words (you know, um, like)? Did you include a call to action?

Note what to change and go for it again! Think about how you'll answer easy and hard questions.

### YOU are the expert!

Your story belongs to YOU. You own it. While opinions and priorities may be different for your audience, no one can question your experience. You get to decide what parts of your story matter the most, what to share, and when.

# Who's Listening?

*Audience-specific tips*



## Media

Do your research to understand the reporter's audiences. Read their past articles or watch prior interviews and get a sense of what's important to them.



## Government Representatives

Create and nurture relationships with your local, state and federal representatives and their staff, and connect your rare disease story to the bigger picture.



## Social Media Followers

Include photos or images in your Facebook or Twitter posts to increase engagement, or share your story on Instagram. A picture is worth a thousand words!



## Teacher, Principal or School Nurse

Have your go-to resource (an article, pamphlet, toolkit, etc.) ready to help explain your or your loved one's rare disease and any needs resulting from the condition.

## Do These Things for an Impactful Story

1. Offer background info, expert resources
2. Get your key messages in early
3. Show your audience how your story applies to them
4. Be concise – less is more!
5. Be authentic – don't memorize your answer
6. Balance fact and emotion



## Doctors

Build and maintain a care notebook to keep all documents, records, notes and important information all in one place.



## Family Members or Friends

Find a way to talk about your condition in a way that makes sense to them. Compare it to something they might understand better, or talk about how the disease affects your everyday life.



## Employers or Coworkers

You don't have to tell your employers or coworkers about your disease if you don't feel comfortable. But if you are in a supportive work environment, discussing your needs can be beneficial for your overall performance.

**“When we share our stories, what it does is it opens up our hearts for other people to share their stories. And it gives us the sense that we are not alone on this journey.”**

*- Janine Shepherd, author*