

UOAA Crafting Your Story Workbook

Your success as a patient advocate has everything to do with how you tell your story. This workbook will guide you through exercises that establish your credibility and expertise, find common ground with your legislator, and back up your story with evidence, data and facts.



Who are you?

Your introduction will let the legislative aide know exactly who you are and why you are asking for their time and attention. As a constituent, you are one of the most important voices to give feedback to your legislator.

Write a brief introduction about who you are as a patient or caregiver, and what your connection is to ostomies or continent diversions. Examples: "I am a patient with an ostomy." "My child has had a continent diversion for more than 10 years and I am her primary caregiver."



Write about who you are outside of your identity as a patient or caregiver.

Be sure to include where you are from, since being a constituent is an important part of building a connection with your legislator's office. Example: "I am a parent of two. I am a volunteer with a local rescue organization. I've lived in Vienna, VA for more than 10 years."



Who is your legislator?

Building a personal connection with your legislator's office is a great way to establish common ground and can completely change the tone of an advocacy meeting. When you research your legislator, you can find information about their views on policy issues that affect you, and possibly some unique connections you might have with them.

What are your legislator's views on healthcare issues?

Search online for your State or Federal legislator's personal website. Most sites will include news releases and statements on issues or priorities. Make note of the health-related priorities the legislator supports, even ones that are not directly related to ostomies. Sharing this information with the legislative aide can impress them that you are familiar with the legislator's views, and you can use it to ask for support for related topics that affect you and your community.

Examples: "My legislator supports equitable access to healthcare, Pharmacy Benefit Manager (PBM) and insurance reform, and funding for medical research."



OPTIONAL: Are there any personal connections you have with your legislator in your background or your community?

Examples: "My child graduated from the same school as the Senator's children." "I was happy to meet the Representative at our local Memorial Day event last year."



OPTIONAL: Is your legislator on any committees? Have they introduced or co-sponsored any healthcare-related bills? How are those bills similar to UOAA's current advocacy agenda?

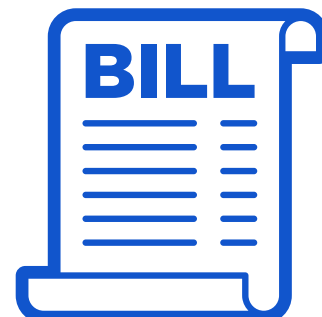
Committee members are a very important part of the legislative process. Each bill introduced will be referred to a different Congressional Committee. It's up to the members of that Committee to hold hearings, review the bill and determine if the bill will make it "out of Committee" and to a vote.

Knowing if your legislator is on a Committee can help you make a stronger plea for their assistance to pass the bill.



For Federal legislators, you can find this information on [Congress.gov](https://www.congress.gov). Use the search bar to search for Members by name. Below their photo will be tabs with Activity and Committee Assignments. To find State legislator Committee assignments and bill activity, navigate to your state's official legislative website.

Make note of what bills the legislator has recently introduced, co-sponsored or voted for. Are they bills that will impact your life as a patient, caregiver or your community?



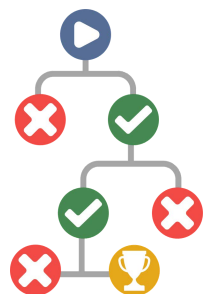
Why are you motivated?

Your “why” — aka your motivation — is your connection to the topic you’re discussing. What are the experiences in your life that drove you to create change? What are the possible benefits for yourself and other patients?

Bullet point your medical journey

You can make short, bulleted notes chronologically or categorize by major medical diagnoses, emergency visits, or surgeries.

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Summarize your bullet points in one or two sentences about what you have experienced in your patient or caregiver journey. Use this space to explain your medical diagnoses or issues in common language that’s accessible for the legislative aide. *Example: “It took a long period of trial and error to find the proper ostomy supplies for my pouching system to achieve a good seal to prevent leaks. My skin was also allergic to several products. I’ve been stable on my current ostomy system for 6 years and it is crucial that I maintain access to these life-saving supplies.”*

Your “Why” is what drives you to create change.

Personalize your story

This is where you start to put a human face to the issues that you are addressing with your legislator. Being able to paint the picture with words helps your story to become memorable. Think of two or three personal experiences that relate to the subject of the bill or policy or issue you are advocating on. Describe them in unique detail. *Examples: "When I ordered my ostomy supplies through my distributor, they substituted a different brand without my approval. Within days I was dealing with leaks, skin breakdown, and the anxiety of not knowing when I could next leave the house. Every day became a guessing game: will this pouch hold, will my skin react, will I make it through the day without embarrassing myself? I was forced to miss a major work presentation and a family reunion, all because of a non-medical decision by my distributor."*



Making your story accessible

Using basic language and humor can make your story easier to relate to.

Mixing the heaviness and seriousness of your medical journey with humor and lightness in a natural way can make an advocacy conversation feel easier. Please use your best judgement to determine if humor is needed during your meeting.

Inclusive language, such as "we, us and our," can show the legislative aide that you represent a larger population of patients and constituents, making your story more impactful. *Examples: "Our ostomate community in your district/state is counting on your support for these reforms." "My ostomy support group is located in your district and this is important to us."*

Include any jokes, anecdotes or inclusive language below that can help bring personality and if needed, lightness to your story.



Please refrain from taking sides politically. The topics you will discuss are for the community at large.

What are you asking for?

So far, you've come up with an introduction for yourself, found connections with your legislator and their health priorities, and written your story in a brief and engaging format. Now, you need to connect your personal, lived experience with what you are asking the legislator to do.

Patient stories are often filled with injustices and harm, and we often wish that things might have gone differently for us throughout our journeys. However, not every issue has a legislative solution. Try to ensure that your story and the experiences that you are sharing are aligned with a clear legislative ask: either a bill, funding request or federal/state oversight or policy reform.

Look up UOAA's legislative priorities. Do you have direct experience with any of the issues these advocacy campaigns are trying to fix?

You can look up UOAA's public policy and legislative priorities online at ostomy.org to better understand what you will be advocating for in your advocacy meetings. *Examples: "My ostomy supplies are not covered by my insurance." "Recent Medicare changes will reduce access and choice to the ostomy products and suppliers I rely on." "My health was jeopardized by delays in care due to unnecessary prior authorizations and step-therapy required by my insurance company." "I am unable to afford the co-pays on my life-saving medication, and my financial future is in jeopardy because of the cost of my medical care."*

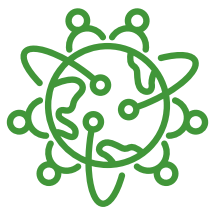


How would your life have improved if this legislation had been in effect or funding had been granted?

How will your life be impacted if policy is implemented (positive or negative?) *Examples: "When this regulatory change is implemented, I'm concerned the in-network suppliers won't carry every product and I may not have access to all of the products that I need for my pouching system." "If I use the wrong products, I won't achieve a proper seal. This will lead to pouch leakage and an embarrassing situation which affects my mental health and may cause a serious skin complication which can lead to further hospitalization."*



What about your story is universal, that almost all other patients in your situation experience? This will help your legislative aide understand the scope and impact of the issue you are discussing. *Examples: "Ostomy supplies are not a one-size-fits-all medical device. Each and every ostomate must be custom fit by an ostomy nurse to ensure proper fit and function." "Every patient with chronic illness knows the pain of having to wait through extensive insurance delays and denials for life-saving medication."*



What data or facts support your legislative asks?

UOAA has a resource library, action alerts and advocacy campaign links online at ostomy.org. These can help you find more facts and data about issues you are advocating for, including position statements, infographics and materials to better understand the issue. *Examples: "In the United States alone, as of 2015, the estimated numbers of IBD patients are approximately 1.3% of the population and counting, or upwards of 3.1 million people." "Almost half of respondents in a national study experienced non-medical switching of ostomy supplies."*



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Putting it all together

Look back over the work you've done above, and shorten each section into one or two sentences. Start combining the pieces together here.

Once you have a firm draft of your story, you can edit it down to a short “elevator pitch” length, which should be close to 2 minutes. Read your story out loud with a timer. Does it feel like it flows smoothly from one topic to another? Do you repeat anything or find that any section doesn’t have the right emphasis on what you’re trying to say? Editing your words down to 2 minutes can be a challenge, but try your best to find the sentences and phrases that represent your patient or caregiver journey the best.

You can also practice adapting your story to different lengths and topics. Most legislative meetings will last less than 30 minutes. If you are working in a group, you will have far less time than that for your personal story. It is not uncommon to have several versions of your story that you can share based on how much time you have, whether your legislator is already supporting some of your bills or policy change or funding requests, and who is with you in your meeting. In putting these pieces together, is your story: clear, honest, impactful, unique, short and productive?

Here is an example of a suggested format for how to build your story's flow and progression.

1. Begin with your introduction, who you are as a patient and as a person, and your connection with your legislator.
2. Move on to your patient/caregiver experiences and your medical journey.
3. Tie your experiences with UOAA legislative or advocacy asks.
4. Share data/facts that emphasize the importance of your asks.
5. Conclude with why this matters to you and others, and a thank you for their time.

