

# VEDA

## VESTIBULAR ADVOCACY TOOLKIT



YOU CAN BECOME AN INFLUENTIAL ADVOCATE  
FOR IMPROVED VESTIBULAR PATIENT  
DIAGNOSIS AND TREATMENT

# HOW CAN I ADVOCATE FOR VESTIBULAR DISORDERS?



## FIND YOUR ELECTED OFFICIALS

Visit:  
[commoncause.com/take-action/  
find-elected-officials](https://www.commoncause.com/take-action/find-elected-officials)



## CONTACT YOUR ELECTED OFFICIALS

Call\*, schedule an in-person meeting, and attend public forums.  
\*Dial 1-844-872-0234, press 1, then enter your zip code.



## WRITE YOUR ELECTED OFFICIALS

See our suggested letter template and customize it with your personal story and details of the relevant issue.



## STAY INFORMED

Join VEDA's mailing list to receive advocacy updates.

[vestibular.org/vnews](https://www.vestibular.org/vnews)

FOR MORE TIPS VISIT

[VESTIBULAR.ORG/ADVOCATE](https://www.vestibular.org/advocate)

JOIN THE CONVERSATION AT [FACEBOOK.COM/VESTIBULARVEDA](https://www.facebook.com/VestibularVEDA)

# CHECKLIST FOR WRITING AN EFFECTIVE LETTER

## CONTENT

### ✓ PARAGRAPH ONE

Opening Statement. This is a good place to state that you are a constituent. You should also identify the reason you are writing your letter and what you would like from the official. If you have a specific bill you would like your official to act upon, request their action in regards to that bill.

### ✓ PARAGRAPHS TWO AND THREE

Use these paragraphs to clearly discuss the issue as it relates to you and your community. These paragraphs should use a combination of facts, research, and personal stories to support the points you are making, presenting information that is personalized and poignant. Remember, less is more. Keep your letter to one single space page.

### ✓ PARAGRAPH FOUR

Identify what you are asking from the legislator. Be specific. [Example: I urge you to support (your issue here) by voting in favor of XXXX this session.] You do not have to identify a particular piece of legislation, but you can if you are aware of one that addresses the issue at hand. Finally, provide information for the elected official on where he or she can find out more about the issue and VEDA (e.g. vestibular.org).

## FOLLOW UP

- ✓ It is always helpful to call your elected official to follow up after sending your letter, e.g. "Hi. My name is \_\_\_\_\_. A few weeks ago I sent you a letter about \_\_\_\_\_. As one of your constituents, I hope I can count on you to act on this important issue."
- ✓ As new developments on the issue arise, you may want to send another letter updating your elected official, especially if there is additional action that is required.
- ✓ Sign up for your elected official's email list so you can stay up-to-date on their position on your issue.
- ✓ Attend any public meetings held by your elected official to personally share your views with them.



# SAMPLE LETTER TO YOUR ELECTED OFFICIAL

Your Full Name  
Street Address  
City, State Zip  
Phone Number

Today's Date

**The Honorable** (Official's name here)  
**Role of the Official**  
**Office Mailing Address**

**Dear** (Elected Official's Name):

**I am a constituent of** (location) **and a vestibular** patient/healthcare provider. **I am writing to urge you to...**  
(Insert issue you are writing about, e.g. support increased funding for research into the diagnosis and treatment of inner ear and brain balance disorders...or...support better Medicare coverage for vestibular testing and treatment).

**The vestibular system includes the parts of the inner ear and brain that process sensory information involved with controlling balance and eye movements. According to the National Institutes of Health (NIH), 40% of the US population age 40 or older will experience a balance disorder in their lifetime. Dizziness is the third most common major medical symptom reported, yet the majority of cases remain unexplained. More than 12 million people over 65 experience a dizziness or balance problem that significantly interferes with their life. Annual spending on patients with dizziness in emergency departments is \$4 billion.**

[Insert BRIEF explanation of your personal story, e.g. I was diagnosed with XXXX in Year, after XX months and consultations with numerous doctors. Although my symptoms are invisible, they impact my life dramatically. I cannot (insert activities, such as work, care for myself, attend social functions), and often feel (insert emotional impact, e.g. anxiety because I never know when I will experience a disabling vertigo attack).]

**Your support for** (insert issue, e.g. increased research funding to the National Institutes of Health) **is crucial to reducing the time it takes for vestibular patients like me to get an accurate diagnosis and effective treatment.**

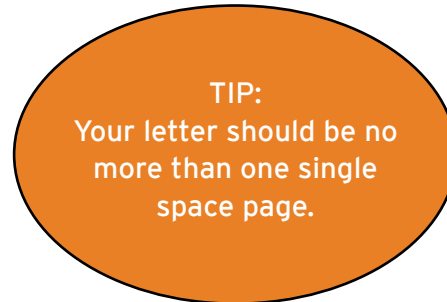
**Thank you for your time and consideration.**

**Sincerely,**

Hand Written Signature (this is important because it shows that the letter came from a real person)

Printed Name

P.S. You can learn more about vestibular disorders at [vestibular.org](http://vestibular.org).



# REACHING OUT TO YOUR ELECTED OFFICIALS

## PHONE CALL SCRIPT

Good Morning/Afternoon.

**My name is [Your Name Here]. I have been a constituent in [name of the elected official you are calling]'s district for [# of years you have lived in the district] years. I am reaching out to you because I am a vestibular [patient/healthcare professional] and I know firsthand the devastating impact these conditions have on the lives of patients and their loved ones.**

According to the National Institutes of Health, 40% of the US population age 40 or older will experience a balance disorder in their lifetime. Dizziness is the third most common major medical symptom reported, yet most cases remain unexplained. According to one study, 50% of vestibular patients can no longer work. Annual spending on patients with dizziness in emergency departments exceeds \$4 billion.

**As a constituent who has [struggled with vestibular disorders/treated people who have struggled with vestibular disorders], this is a very personal issue to me. I would like the chance to tell [name of the elected official you are calling] directly how important it is to bring vestibular disorders to the center stage of the national health policy discussion. We desperately need more funding allocated to research into vestibular diagnostics and treatment. In addition, we need to make sure that testing for vestibular disorders is covered by Medicare and other insurance companies.**

I am a member of the Vestibular Disorders Association, the leading national organization people turn to for help with vestibular disorders. They are an authoritative resource, publishing information that is clear, reliable, and scientifically objective. You can learn more about vestibular disorders by visiting their website at [vestibular.org](http://vestibular.org).

I appreciate you taking my call. Please let me know of any public meetings that are coming up, or if there is a time that I could speak to [name of the elected official you are calling] directly. You can reach me at [your phone number and/or email address].



# MEETING TIPS

## HOW DO I GET A MEETING WITH AN ELECTED OFFICIAL?

1. Look on the Elected Official's Website for public meetings that are scheduled in your area.
2. Use VEDA's Elected Official Phone Call Script and ask for a meeting.

## HOW CAN I MAKE THE MOST OF MY MEETING?

1. Be aware of your physical limitations. If you tire easily, make sure to rest beforehand. You might want to bring a friend or family member to support you. If you need special accommodations, let the legislator's staff know in advance.
2. Come prepared. Bring information on the topic you hope to discuss. This information is best presented through a blend of data and your personal narrative. Look on VEDA's website ([vestibular.org](http://vestibular.org)) for the information on vestibular disorders that is most relevant to your personal experience. Print it out and share it with your representative.
3. Ask questions. You're there to present your position AND to find out what the position of your representative is. Write down your questions in advance. This will show that you are thoughtful and prepared.
4. Present yourself professionally. Don't be argumentative; state the facts, but also show your passion for the need to raise awareness about vestibular disorders. Diplomacy is the best approach. Wear clothes that are clean and tidy (no sweat pants or t-shirts). Over dressed is better than under dressed.

## MAKE CONNECTIONS

1. While at the meeting try your best to reach out to staff who handles specific policy issues like healthcare. Leave information with them and try to form a connection you can use later.
2. Ask, "Is there anyone in particular I should be talking to about my concerns about healthcare policy issues?"

## I HAD A MEETING, NOW WHAT?

1. Follow up!
2. Call, email or write officials and staff you met with to reinforce how passionate you are about VEDA's mission and why it should get national attention. Thank them for their time, and express your interest in staying in-the-loop on future healthcare policy issues.

## SHARE YOUR HARD WORK!

1. You took the time to attend or set up a meeting. Make sure to share your efforts with family, friends and VEDA staff to encourage others to reach out to their representatives as well.
2. Take a photo of yourself with your representative and share it on your social media outlets with a summary of the issue and your visit. Tag VEDA in your post (@vestibularveda)
3. Contact your local newspaper and offer to share your story. They are often interested in how legislators are interacting with their constituents. Make sure to refer them to [vestibular.org](http://vestibular.org) for more information.