

# Advocacy 101: Raising your voice as a patient

**Advocate** *noun*

**/ˈadvəkət/ - a person who openly speaks or writes to support a cause**

Thousands of PatientsLikeMe members say they're interested in advocacy or doing more for their community. What does it mean to be an advocate? And how can you get started? Advocacy comes in all shapes and sizes, depending on your interests and what works best for you. Together with our Team of Advisors – a group of highly active members and advocates in their condition communities – we're sharing pointers on where to begin.



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"If you tell one other person your story – you are an advocate."

## Share your story

Believe it or not, just by sharing your story and experiences with others, you're an advocate. Spreading the word about your reality is a great way to raise awareness.

- Connect online with other PatientsLikeMe members to discuss common challenges, possible solutions and advocacy ideas.
- Open up to your care team to give a deeper sense of the patient perspective.
- Share with those in your local community, religious group, family and friends.
- Reach out to your local non-profit organization and join a support group for those with your condition.

"Identify your interests and passions – the things you would want to advocate around (such as research, patient rights, access to care, understanding, stigma reduction, etc.) – this will help you pinpoint the right fit for you."

## Discover your interests and play to your strengths

Advocacy isn't one-size-fits-all – but there are opportunities just about everywhere. Take time to identify your passions and interests to find the best fit.

- Do you like to write? Start a blog using a free site like Wordpress or Blogger.
- Are you interested in fundraising? Track down your local condition organization for fundraising events or walks.
- Do you like to plan things? Volunteer to help organize an upcoming event.
- Are you interested in educating others? Share interesting research studies, articles or blogs with people.
- Are you social media-savvy? Start an advocacy account, interact with advocacy pages on Twitter or give others a glimpse into your life on Instagram, if you're open to it.



BERNADETTE // LIVING WITH PARKINSON'S

"Look at organizations related to your condition, ask your doctors/providers about community groups, look at your condition communities or your geographical communities."

## Reach out! Network with others to get more involved

Ask people in your life to help you reach your goals. Don't be afraid to seek out connections and build an advocacy team (large or small).

- Talk to your care team about ways that you can help other patients or advance your cause.
- Join or connect with your local organization for your condition. They probably have everything from pamphlets you can hand out to events you can participate in, plus support groups in your area (with others who'd like to be advocates!).
- Talk with other patients. Ask how they got started and what they like to do, and even put a group together to tackle your goals together.

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