



How to Advocate for Yourself: Advice from ACHA's Peer Mentors

Whether self-advocacy is a new practice for you or you are a seasoned advocate, these points and resources will help to serve as a guide for being your own best advocate.

- **Find an ACHD specialist** by using [ACHA's Clinic Directory](#); search by zip code or state. [Check out this resource](#) if you're not sure why you should see an ACHD specialist.
- **Get familiar with the guidelines for ACHD care** by reviewing patient-friendly updates. You can find the [most recent version](#) (to be updated in 2026) on our website.
- **Bring a trusted loved one to appointments** to take notes. Use a note taking app or notebook to capture your conversation with your ACHD provider during or right after your visit. Ask if you can record your conversation. Review your after-visit summary.
- **Request a virtual visit.** This can be especially helpful if you live far from an ACHD clinic.
- **Ask how to best communicate with your provider:** by patient portal, phone call, email?
- **Create an emergency room plan** with your ACHD provider. ACHA also created [this handy guide](#) to get the conversation started with your provider and family.
- **Have a hospital admission plan** in mind with your ACHD provider.
- **Create a living will** and give a copy to all your doctors.
- **Keep a health passport handy** with details you might need but have trouble remembering during stressful moments. Two options are [ACHA's passport](#) and [EmpowerMyCH](#).
- **Ask about emotional support services** available at your hospital. Some have an integrative medicine department, and you may qualify to receive services at little cost. You can also request peer support through ACHA's [Heart 2 Heart Peer Support Program](#).
- **Know what to do if your health insurance referral or coverage is denied** (and other tips).
 - Ask your ACHD provider for justification for all referrals or medications *in writing*.
 - Submit an appeal or grievance. Give your insurance provider a letter from the referring physician, the ACHD provider, along with the ACHD Care Guidelines.
 - Check with your plan to see how long you have to appeal or file a grievance. Many insurance companies have a 30-to-60-day window.
 - Request a Peer-to-Peer Review between your ACHD provider and the insurance company for your appeal or grievance.
 - If coverage for a medication is denied, reach out to the manufacturer directly. Many work with people who have income above the poverty level, and some provide the medication for free if you participate in a research study. You may also be able to find a coupon online; ask your pharmacist if you can't find one. You may also confirm with your provider that they completed any prior authorization.





- Review the itemized bill from your visits. Speak to your healthcare provider and contact your insurer about any charges you wish to dispute. Write down who you spoke to, the date, and the time of your call. Contact a credit-reporting agency to ensure your disputed bill does not impact your credit score.
- If your provider no longer accepts your insurance plan, complete a continuity of care request form.
- Consider reaching out to the hospital's financial assistance department if you have excessive charges due to deductibles, co-pays, or similar expenses.
- If you're feeling uncertain or just want another point of view, **ask for a second opinion**. Many providers welcome second opinions and will make a referral.
 - When receiving a second opinion, 28% of patients were given a new diagnosis, and 72% had their treatment plan changed.
 - Having your treatment plan modified isn't a sign that any of the past plans were wrong! They are just different, and this gives you the opportunity to select the best treatment plan for you.
 - You may not need to tell your provider you are seeking a second opinion.
- **Use patient education materials** to build confidence and become an expert! ACHA's [webinar library](#) is a great place to start.
- **Wear Medical ID bracelet** jewelry that communicates a way to reach your provider in case of emergency.
- **For even more helpful resources**, visit ACHA's [Patient Resource Directory](#). If you know of a good local resource and you don't see it listed, [let us know](#).

