

Patient Self-Advocacy Tips for People with Hypersomnia (PWH) and Related Disorders

Hypersomnia covers several rare sleep disorders that are not considered to be in the mainstream of health care, which means they are sometimes hard to diagnose and treat.

Self advocacy means representing yourself to the best of your ability and being proactive about your care. Becoming involved in the decision-making process with your healthcare provider about your care and treatment can help you feel confident that everything is being done to manage your symptoms. Studies have also shown that people who advocate for themselves feel more in control of their medical conditions and their lives, are more satisfied with their care and have better outcomes. Accordingly, this guide has been prepared to help persons with hypersomnia and sleep related disorders become their own advocate, to the best of their ability.

Becoming an Effective Self-Advocate

There are 5 basic steps to Self Advocacy:

1. Education
2. Communication
3. Decision making
4. Negotiation
5. Support

1. EDUCATION

The more you understand about your sleep disorder, the more effectively you will be able to advocate for yourself.

The Hypersomnia Foundation (HF) website www.hypersomniafoundation.org is easy to use and has a wealth of information and education that includes research articles written or summarized in layman's terms. The site also has a directory of providers who are familiar with hypersomnia and related disorders, a comprehensive glossary of medical terms, and much more. HF's website is frequently updated with new resources and articles.

Here are some resources to help answer questions you may have and increase your knowledge about hypersomnia and related sleep disorders:

- ❖ **What is hypersomnia? What are the related sleep disorders?**
<https://www.hypersomniafoundation.org/about-idiopathic-hypersomnia>
<https://www.hypersomniafoundation.org/classification-of-hypersomnias/>

- ❖ **Glossary of medical terms, tests and medications:**
<https://www.hypersomniafoundation.org/medical-terminology/>
- ❖ **Research studies and articles:**
<https://www.hypersomniafoundation.org/category/research/journal-article-summaries/>
- ❖ **HF Social Media** : follow HF on social media (FB, Twitter, Instagram and LinkedIn) to learn the most recent news and updates about IH and other sleep disorders.
- ❖ **Somnusnooze:** HF's monthly free e-newsletter can keep you up to date on all the latest research and resources - sign up at the bottom of the main HF page:
[hypersomniafoundation.org](https://www.hypersomniafoundation.org)

2. COMMUNICATION

a. Preparation is key to effective communication

Keeping track of your own medical records, symptoms, tests, medications, supplements and past appointments will help you to efficiently use your appointment time with your health care providers, allowing you to better focus on current questions and issues.

Here are some examples of how you might keep track of your medical records and other information:

- ❖ **Create your own Personal Electronic Medical File:** There are several apps that you can use to manage all your information. Use the link below for more information and guidelines on choosing the right app for you:
<https://www.healthit.gov/faq/how-can-digital-tools-help-me-manage-my-health-information>
- OR-
- ❖ **Create your own Care/Records notebook:** Create your own notebook or folder to hold all the above information, and take this with you to all appointments. This can take the form of a notebook, folder or binder which holds all of your medical records information, as well as any other information you choose to add (such as a calendar of upcoming doctor's appointments, contact information for your physicians, copies of your prescriptions, copies of your insurance cards, any research articles you think might be pertinent, and any notes you might take). Be sure to carefully organize your documents so that they are easy to locate and retrieve (using tabs and dividers is a good idea).

Whether digital or written, remember to update your Personal Medical File with each appointment, treatment change, symptoms and results.

- ❖ **Obtaining your Medical records:** You are entitled to have a copy of all of your medical records from all of your providers with some exceptions under the HIPPA (Health Information Portability and Accountability Act). So request all of your medical records from all of your doctors. If there are records they cannot

provide, ask and understand why. Read more about your rights here:

<https://www.hhs.gov/hipaa/for-individuals/medical-records/index.html>

- ❖ **Patient Advocate Foundation:** A helpful go-to website if you are having any problems obtaining your medical records <https://www.patientadvocate.org>
- ❖ **Follow recommendations:** Schedule treatments and screenings in a timely fashion. Keep appointments and stay on schedule to the best of your ability. If you can't stay on schedule, contact your health care providers right away.
- ❖ **Follow up:** Be proactive and call your provider to ask for test results. *Keep copies* and add results to your own personal medical records.

b. Communicating effectively* with your provider:

- ❖ **Voice** your concerns, desires and opinions firmly but calmly.
- ❖ **Express yourself clearly, keep it brief and stick to the point** that you are trying to make.
- ❖ **Ask questions.** Write them down before you go to an appointment.
- ❖ **Understand.** Ask your doctor/health care provider to explain if you don't understand something and to write the main points down for you if it is a lot of information.
- ❖ **Repeat back** to the doctor what you think you heard to avoid miscommunications.
- ❖ **Consider taking an advocate**, such as a family member, partner, or close friend with you to appointments. They may be able to help advocate for you, or simply help by listening - it can be easy to miss something that was said, or forget parts of the conversation after you have left your appointment.

*Assertive communication is neither *passive* nor *aggressive*. Learn more here:

<https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/assertive/art-20044644>

3.DECISION MAKING

- ❖ **Use a team approach when making important decisions** such as whether or not to have treatment, enroll in a clinical trial, which physician to choose and when to ask for a second opinion. Discussing these important choices with your primary provider, a family member, partner, close friend or a support group will help to make reaching decisions easier and less stressful.
- ❖ **Second opinions:** Asking for a second (or even third or fourth) opinion from another health care provider can help you in the decision-making process by confirming that your current diagnosis and treatment plan can work for you, or by giving you different opinions so that you can make an informed decision about your treatment plan going forward.
- ❖ **Why you should ask for a second opinion:**
<https://www.verywellhealth.com/top-reasons-to-get-a-second-opinion-4144734>
- ❖ **How to ask for a second opinion**
<http://compasshcsolutions.com/blog/how-to-ask-for-a-second-opinion-without-offending-your-doctor>

- ❖ **List of sleep doctors familiar with Hypersomnias:**
<https://www.hypersomniafoundation.org/healthcare-provider-directory/>

4. NEGOTIATE FOR YOURSELF

As you probably already know, having a sleep disorder means learning to negotiate many aspects of your life - education, health insurance, disability etc.- in order to get your unique needs met. Strive to be your own self-advocate using the same communication skills that you would use with your provider in order to tackle the issues that will affect your quality of life. For example, you may not be able to work full-time and need to transition to disability, you may need extra help in college or you may need to appeal denials of health insurance. Don't be afraid to exercise your rights and hire a lawyer if necessary, to protect those rights. (Ask attorneys that you are considering whether they offer alternative fee arrangements, if your resources are limited.) Here are some links that may help you get started in these areas:

- ❖ **Getting help or managing in school/college:**
<https://www.hypersomniafoundation.org/education-essentials-for-students/>
- ❖ **Workplace accommodations:** <https://askjan.org/disabilities/Sleep-Disorder.cfm>
- ❖ **Employee rights:** <https://askjan.org/publications/individuals/employee-guide.cfm>
- ❖ **Disability resources:**
<https://www.hypersomniafoundation.org/category/disability/>
- ❖ **Health Insurance:** Know what your insurance does and does not cover. If you don't have insurance, ask the doctor and/or their staff if they offer any special rates or options. You have the right to appeal a denial by your insurance company. If your appeal is turned down, consider contacting your state insurance commission, as they may be able to overrule the insurance company. But you must complete the insurance company's appeal process first.
<https://www.hypersomniafoundation.org/nord-guide-for-making-your-health-insurance-work-for-you/>
- ❖ **Social Security resources:** <https://www.ssa.gov/disability/>

5. SUPPORT:

Coping with a chronic condition is stressful and challenging! Seek out support for yourself as you go through the process of diagnosis and treatment. Here are some suggestions for finding support:

- ❖ **Read some of the shared “personal journey” stories** from people with IH. Perhaps share your own story:
www.hypersomniafoundation.org/share-your-journey/gistry/
- ❖ **Seek out a support group** of people who have the same or similar diagnosis as yourself (and consider a support group for your caregivers). There are virtual support groups online. (HF does not organize or endorse any particular group, so search online and on Facebook.) It might be helpful to observe a group's interactions before posting your own comments.
<https://www.hypersomniaalliance.com/on-line-support-groups>
- ❖ **Ask for a referral to a licensed therapist** to help you cope with your chronic condition. Learn more about how therapy can help here:

<https://www.hypersomniafoundation.org/mh-help/> and here:
<https://psychcentral.com/psychotherapy/>

- ❖ Here is a great article written in the NY Times about why it is as important to take care of your mental health when you are diagnosed with a chronic condition:
<https://www.nytimes.com/2019/02/18/smarter-living/five-things-i-wish-i-knew-chronic-illness-crohns-disease-ibd.html>
- ❖ **Attend a Patient Education Day:** Announcements will be on the homepage of the HF web site and in SomnusNooze.

Become empowered and involved in future research:

Join the CoRDS registry (Coordination of Rare Diseases at Stanford): By enrolling in the registry, you will be helping with research into the causes and treatments of hypersomnias. Follow this link to answer all of the questions you may have and to sign up:

<https://www.hypersomniafoundation.org/join-the-patient-rehttps://>

Consider Donating to the Hypersomnia Foundation: Your generous donation to the HF will help raise more awareness and help support ongoing medical and scientific research. The HF is a non-profit 501(c)(3) tax-exempt organization, and is totally dependent on donations and grants.

<https://www.hypersomniafoundation.org/donate/>

Remind yourself that you are coping to the best of your abilities - don't be hard on yourself! Be proud of every success and remember you are not alone. The Hypersomnia Foundation is here to support all people with idiopathic hypersomnia and related sleep disorders.