Self-Advocacy Tips
For People with Idiopathic Hypersomnia (IH) and Related Disorders

Hypersomnias include IH and several related sleep disorders that are not considered to be in the mainstream of health care, which means they are sometimes difficult 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 possible is being done to manage your symptoms. This guide has been prepared to help people with IH and related disorders identify ways they can enhance their skills at advocating for themselves.

Becoming an Effective Self-Advocate

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, has a wealth of information, and is frequently updated with new resources and articles. Here are some resources to help answer questions you may have and increase your knowledge about IH and related sleep disorders:

- **What is idiopathic hypersomnia?**
  www.hypersomniafoundation.org/about-idiopathic-hypersomnia

- **What are the related sleep disorders?**
  www.hypersomniafoundation.org/about-related-sleep-disorders

- **Glossary of medical terms:**
  www.hypersomniafoundation.org/medical-terminology

- **Journal articles:**
  www.hypersomniafoundation.org/category/research/journal-article-summaries

- **Research articles:**
  www.hypersomniafoundation.org/category/research

- **HF Social Media:** Follow HF on social media (Facebook, Twitter, Instagram, LinkedIn) to read 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 the latest research and resources – sign up in the yellow banner at the bottom of any HF web page. Check out past articles at www.hypersomniafoundation.org/somnusnooze-articles
2. Communication

Preparation Is Key to Effective Communication

Keeping track of your own medical records, symptoms, tests, medications/supplements, past appointments, etc. will help you to efficiently use your appointment time with your healthcare providers, allowing you to better focus on current questions and issues. Ask for help from a supporter or start on your own with small steps if this seems overwhelming. Start with what you can manage, such as keeping a list of doctors first, then adding a list of medications, and go from there.

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

• **Create your own care/records notebook.** Organize your medical information by creating your own notebook, binder, or folder (either physical or on your computer, with scanned/downloaded documents that may be made available to the cloud), which you can take to all your appointments. In addition to your medical records, you might include a calendar of upcoming medical 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).

• **Keep your own personal medical diary, and take this with you to appointments.** Jot down notes daily or as you’re able. Include, for example, your response to medications (Do they work? How do they make you feel? Side effects? Any changes in your symptoms?) This diary can help you to answer healthcare providers’ questions accurately.

There are several apps out there to help you keep your medical records in order but none that help you store all of the above. Use the following link for more information and guidelines on choosing the right app for you: www.healthit.gov/faq/how-can-digital-tools-help-me-manage-my-health-information

Whether digital or written, remember to update your personal medical file with every appointment, treatment change, new symptom, and test result.

• **Obtaining your medical records:** you are entitled to obtain a copy of all of your medical records from all of your providers, with some exceptions, under the HIPAA (Health Information Portability and Accountability Act). If there are records they cannot provide, ask and understand why. Read more about your rights at www.hhs.gov/hipaa/for-individuals/medical-records/index.html.

There may be a fee for this service from each provider, especially if you are requesting your entire medical record, as opposed to just a few documents. However, one of your providers (often a primary care provider or another of your main providers) may be willing to request all your records from your other providers, so that you can obtain your entire medical record for one fee. Once you have your entire past records, you should be able to request single documents going forward, which are usually provided without a fee.

• **Patient Advocate Foundation:** a helpful go-to website if you are having any problems obtaining your medical records is 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 healthcare 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.
Communicating Effectively* with Your Provider

It is extremely important that you and your healthcare provider have the same understanding of your visit and that it is recorded accurately in the provider’s notes. In addition to helping ensure that you follow your provider’s recommendations for your health, accurate record-keeping is important for disability, social security, FMLA, etc. and can help ensure appropriate insurance coverage. An effective app for recording your doctor visits (with their permission) can be found at [www.medcorder.com](http://www.medcorder.com). It may also be helpful to prepare a brief written update, possibly including discussion points, for your provider to include in the record of your visit.

**Tips for Effective Communication:**

- **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 healthcare provider to explain if you don’t understand something and to write the main points down for you if needed.
- **Repeat back** to the doctor what you think you heard, to help avoid miscommunications.
- **Consider taking a supporter**, such as a family member, partner, or close friend with you to appointments (or have them join by phone). They may be able to help advocate for you, or simply help by listening and taking notes – 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 at [www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/assertive/art-20044644](http://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 1) whether or not to have a treatment or enroll in a clinical trial, 2) which physician to choose, and 3) 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 can help to make reaching decisions easier and less stressful.

Second opinions: Asking for a second (or even third or fourth) opinion from another healthcare 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.

The following links will help with this process:

- **Why you should ask for a second opinion:**
  www.verywellhealth.com/top-reasons-to-get-a-second-opinion-4144734

- **How to ask for a second opinion:**
  http://compasshesolutions.com/blog/how-to-ask-for-a-second-opinion-without-offending-your-doctor

- **List of healthcare providers familiar with hypersomnias:**
  www.hypersomniafoundation.org/healthcare-provider-directory

4. Negotiate for Yourself

Having a sleep disorder means learning to negotiate many aspects of your life (e.g., education, work, health insurance, disability, etc.) in order to meet your unique needs. Here are some links to get you started in these areas:

- **Getting help or managing in school/college:**
  www.hypersomniafoundation.org/education-essentials-for-students

- **Workplace accommodations:**
  www.hypersomniafoundation.org/have-workplace-questions-check-out-Jan

- **Employee rights:**
  https://askjan.org/publications/individuals/employee-guide.cfm

- **Disability resources:**
  www.hypersomniafoundation.org/category/disability

- **Social Security disability resources:**
  www.ssa.gov/disability

- **Health insurance:**
  www.hypersomniafoundation.org/nord-guide-for-making-your-health-insurance-work-for-you. 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 denied, 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.

  Don’t be afraid to exercise your rights and hire a lawyer, if necessary, to protect those rights. If your resources are limited, ask attorneys that you are considering whether they offer alternative fee arrangements.
5. Support

Coping with a chronic condition can be 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 hypersomnias. Perhaps share your own story: [www.hypersomniafoundation.org/personal-journey-stories](http://www.hypersomniafoundation.org/personal-journey-stories)

- **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, such as [www.hypersomniaalliance.com/on-line-support-groups](http://www.hypersomniaalliance.com/on-line-support-groups). It might be helpful to observe a group’s interactions before posting your own comments. (HF does not organize or endorse any particular group, so search online and on Facebook.)

- **Ask for a referral to a licensed therapist** to help you cope with your chronic condition. Learn more about how therapy can help here at [www.hypersomniafoundation.org/mh-help](http://www.hypersomniafoundation.org/mh-help) or [https://psychcentral.com/psychotherapy](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: [www.nytimes.com/2019/02/18/smarter-living/five-things-i-wish-i-knew-chronic-illness-crohns-disease-ibd.html](http://www.nytimes.com/2019/02/18/smarter-living/five-things-i-wish-i-knew-chronic-illness-crohns-disease-ibd.html).

- **Attend an HF event**: [www.hypersomniafoundation.org/conferences-events](http://www.hypersomniafoundation.org/conferences-events)

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**Become Empowered and Involved in Future Research**

**Join the HF’s registry at CoRDS** (Coordination of Rare Diseases at Sanford): 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: [www.hypersomniafoundation.org/registry](http://www.hypersomniafoundation.org/registry)

**Participate in other research studies (including clinical trials)**: [www.hypersomniafoundation.org/research-studies](http://www.hypersomniafoundation.org/research-studies)

**Consider donating to the Hypersomnia Foundation**: Your generous donation will help raise more awareness and 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. [www.hypersomniafoundation.org/donate](http://www.hypersomniafoundation.org/donate)

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**Remind yourself that you are coping to the best of your abilities** – try not to 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.