

Tips for Parents of K-12 Students with Idiopathic Hypersomnia

The following suggestions were created by a group of parents of K-12 students with idiopathic hypersomnia (IH) who vary in age from 13 to 17. Be sure to consider your child's age when referring to this guide.

1. Be informed about your child's illness.

- Awareness is key for both you and your child.
- Learn as much as you can about your child's illness. Search for information and resources on IH, so you are aware of and understand the symptoms.
- Learn and get help from an IH support group.
- Talk with your child's doctor about the diagnosis and symptoms. If the conversation is not helpful, search for a doctor who is.

2. Let your child know you are and will be there for them.

- Understanding and support are key in your child's journey. Believe in, listen to, understand, and be concerned for your child.
- Reassure your child that the symptoms are not their fault and that you will get them the best help possible.
- Be empathic and compassionate: let your child know that you understand that their symptoms are affecting their lives and how hard it has to be to live with these symptoms; that you will continue to do all you can do to help your child; and, that you also wish they didn't have this illness and hope for changes soon.
- Involve your child age-appropriately in the decisions being made due to their symptoms.
- Show respect when talking about the symptoms so as not to upset your child.
- Be steadfast in expressing support and love so your child has no reason to doubt you.
- You know your child best and can see the physical and emotional toll this illness is taking on them. You also know that it is taking a toll on you. You are a team, so let your child lean on you for support, as you draw strength from your child's courage.
- Never lose hope.

3. Handle situations so your child does not feel guilty about or blamed for their symptoms.

- Stay calm. Having a confrontation before school can result in a difficult day at school.
- Keep in mind that not every child is "only sleepy" during the day. Some children also experience cognitive effects, such as confusion and loss of focus (aka brain fog). Children with IH may be experiencing this when parents think they are not paying attention or if they are not responding as one would expect.

4. Support your child in sharing their feelings and thoughts about living with IH.

- Be available to your child, and encourage your child to speak freely about how they are affected physically and emotionally. Ask questions such as, *"What's it like when you wake up? Do you get tired at school? If so, when?"*
- Encourage your child to articulate their symptoms and how they affect their daily life.
- When your child prefers not to talk about their feelings, respect their decision and help them become more aware by making observations (*"You look really tired. Are you ok?"*) or asking about a class they took that day (*"How did it go in PE class today? How are things now?"*)
- Have parent-child talks often (*"So, anything on your mind you want to talk about?"* *"How can I make things better or help you?"*).
- If you see a confused or worried look on your child's face, begin a conversation about it.
- If you notice any changes in their symptoms, encourage your child to talk about them.

5. Keep an eye on changes in your child's physical and emotional symptoms.

- When your child isn't feeling well or is tired, believe your child even if you don't see signs of other symptoms.
- If you see changes in your child's symptoms that seem to be getting worse or otherwise concern you, consult your child's doctor. For example, is your child complaining more frequently about being tired or asking to sleep longer in the morning (*"Just five more minutes"*)? Is your child feeling sluggish and taking naps before bedtime?

6. Help your child to keep a scheduled, daily routine as much as possible.

- Keep a log of when symptoms occur and how your child is feeling at the time.
- Work with your child to encourage them to structure their daily lives, so they use their most wakeful times of day to meet the responsibilities of being a student.
- Keep in mind that there may be a lot of changes in your child's sleep and wake patterns. For example, your child may have days that are wakeful and days that aren't.
- Help your child to wake. Some parents have been successful nudging their children; others have lifted their child to lean against them. Ask parents in IH support groups what they do that helps. Consult with your child's doctor.

7. Find positive outlets for when you get discouraged.

- Just like your child, you may have good days and bad days. Be kind to yourself.
- Support is key. Supporters need support, too.
- Get help from a support group on IH.
- Learn as much as you can about your child's illness.
- Never give up. If you do, your child might think you are giving up on them.

8. Advocate for your child.

- This is your child, and you have the responsibility to look out for your child.
- If your child wants to talk with their doctor, arrange an appointment and let the doctor know why.
- If your child is struggling with schoolwork, inform teachers and ask for their help.
- Speak out on behalf of your child and their illness. It is not “just laziness,” or “being sleepy” or “tired.” Their illness is more complex than this.
- Awareness is key. Provide information about idiopathic hypersomnia to those who play an active part in your child's life.

9. Turn negative comments into opportunities to inform others about IH.

- Raising awareness and understanding about IH is the best way to approach negative comments by others.
- Keep in mind that idiopathic hypersomnia is a rare condition, and most people do not understand the symptoms and how they impact your child's daily life.
- Correct inaccurate comments about your child's symptoms by providing information about idiopathic hypersomnia. You can start by saying, “*Well, actually, ...*,” and then share the accurate information.
- Educate your child about how to respond to inaccurate comments, so they can advocate for themselves.

10. Talk with your child's doctor.

- Ask about resources for information and help.
- Discuss these questions:
 - When your child indicates that they are not feeling well, what does the doctor suggest you do about school attendance and activities that day?
 - If your child feels strong effects of the symptoms during the day, what does the doctor suggest you do about early dismissal from school?
 - If you get no response from your child when you try waking them, what does the doctor suggest you do to rouse your child?

11. Keep school personnel informed.

- Keep lines of communication open with school staff before, during, and after your child receives a diagnosis. Be sure to notify the school and the teachers up-front about your child's symptoms and about the diagnosis once it is made.
- Help school staff understand that idiopathic hypersomnia is more than “just being tired,” by providing information about IH.
- Be proactive, and inform the teachers about the symptoms they will be dealing with.
- Ask school staff to inform you about any changes in your child's symptoms at school and how the staff responded to those changes.
- Communicate all symptoms -- small and large -- to help provide a total understanding of idiopathic hypersomnia symptoms to the school staff.
- Be sure to keep everyone who is involved with your child updated on how your child is doing. This re-enforces their understanding of how you advocate for your child.

12. Work with school personnel to ensure the accommodations your child needs.

- Provide the school with a written diagnosis from the doctor as soon as possible.
- Request to meet with school staff to learn about the process for requesting an evaluation for accommodations.
- If your child has a need to take naps during school, inform school personnel, including the nurse and the teachers.
- If your child is too tired to make it to school on time, suggest a later start.
- Ask about and work with school personnel regarding the accommodations and programs available through the school.

Parents offered the following suggestions during the Hypersomnia Foundation Snooze TV broadcasts (2014-2015) and at the 2015 Hypersomnia Foundation Conference. These suggestions augment those identified previously.

13. Choose the Right Pediatrician.

The physician for your K-12 student needs to be able to listen, support, and not discredit the experience your student describes or ignore the symptoms that are affecting daily life or the concerns expressed by the parent(s). The pediatrician's role in your student's life is critical. If the current pediatrician is not respectful of symptoms or supportive of pursuing an accurate diagnosis, find a new doctor!

14. Seek Services.

There are services outside of school that can help your student. For example, your state rehabilitation services office can be of assistance, as idiopathic hypersomnia is a recognized disability. You can contact them to learn information about the services they offer. You can find a list of your state's rehabilitation offices here:

<http://www.fda.gov/downloads/AboutFDA/WorkingatFDA/UCM277757.pdf>.

15. Use the Resources.

Idiopathic hypersomnia is not a behavioral issue, and it's not something that can be fixed with a magic wand. This is a legitimate medical condition that your student cannot help. Connect with others via social media when you:

- Sign up for the Hypersomnia Foundation's SomnusNooze newsletter and access past editions at www.hypersomniafoundation.org.
- Spend time on the Hypersomnia Foundation website to learn more about idiopathic hypersomnia.
- Attend the Hypersomnia Foundation's events.
- Join support groups.

Members of the Hypersomnia Foundation Board of Directors (2017) offer the following suggestions:

16. Medical Alert Safety:

Families are advised to be aware of available medical alert options, which now include medical alerts available on many smartphone lock screens, in addition to traditional alert bracelets or wallet cards. Families are also advised to create a way of communicating with their student should the student need to convey a matter is urgent, e.g., using a coded word or sending a coded electronic message.

17. Directory of K-12 Guides:

Families are advised to know about the contents of the *Education Essentials for Students with Idiopathic Hypersomnia* guides listed in the **K-12 Directory of Guides:**

1. **Considerations When Requesting K-12 Accommodations**
<http://www.hypersomniafoundation.org/wp-content/uploads/Considerations-When-Requesting-K-12-Accommodations.pdf>
2. **Assistive Technology in K-12: A Walk on the Tech Side**
<http://www.hypersomniafoundation.org/wp-content/uploads/Assistive-Technology-in-K-12.pdf>
3. **K-12 Student Success: Physicians Can Make an Important Difference**
<http://www.hypersomniafoundation.org/wp-content/uploads/K-12-Student-Success-Physicians-Can-Make-an-Important-Difference.pdf>
4. **Guide to Requesting Accommodations for K-12 Students with Idiopathic Hypersomnia**
<http://www.hypersomniafoundation.org/wpcontent/uploads/Guide-to-Requesting-Accommodations-for-K-12-Students-with-IH.pdf>
5. **K-12 Academic Resources Guide**
<http://www.hypersomniafoundation.org/wp-content/uploads/K-12-Academic-Resources-Guide.pdf>
6. **Tips for Parents of K-12 Students with Idiopathic Hypersomnia**
7. **Teens Talk**
<http://www.hypersomniafoundation.org/wp-content/uploads/Teens-Talk.pdf>
8. **Resources for Families of K-12 Students with Idiopathic Hypersomnia**
<http://www.hypersomniafoundation.org/wp-content/uploads/Resources-for-Families-of-K-12-Students-with-Idiopathic-Hypersomnia.pdf>

18. Seek Evaluations for Accommodations:

Families are advised to request their child be evaluated for accommodations. If the request for the evaluation or for the accommodations are denied, families are advised to seek a second opinion outside the school system, for example by contacting your local special education **parent advocacy council**, the **Office of Civil Rights of the Department of Education**, a **family advocate** and/or **legal consultation** (with referrals for the latter two from parent advocacy groups).

19. Physician Contact:

Request correspondence from the physician during the assessment for accommodations.

20. Work as a Team:

The Hypersomnia Foundation recommends that parents work with the student and physician together to choose the most useful accommodations, keeping in mind that requesting a few critical accommodations is often better than choosing all potentially helpful accommodations.

21. Work with the School Nurse:

The school nurse is the medical practitioner in a student's daily life. That practitioner needs to be (1) informed about the student's medical diagnosis of IH; (2) provided information about the diagnosis (www.hypersomniafoundation.org), including the IH Standard Characteristics document (<http://www.hypersomniafoundation.org/idiopathic-hypersomnia-standard-characteristics/>) and the K-12 Education Essentials Guides; and (3) informed about the student's needs in a school setting, including but not limited to possibly dispensing medication and providing a space for necessary naps and exercises. In some school jurisdictions/states, the school nurse may be allowed to participate in school meetings (e.g., 504/IEP) for the student.

Approved by Hypersomnia Foundation Board of Directors and Education Legal Counsel

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