

Idiopathic hypersomnia (IH) is a neurological disorder characterized by excessive daytime sleepiness (often with associated cognitive dysfunction), despite getting a full night's sleep or longer. IH patients may experience other symptoms related to the autonomic nervous system, such as feeling lightheaded when standing up quickly, or abnormal regulation of body temperature. People with IH may face a unique set of challenges around the time of an operation or procedure with anesthesia, which may impact their symptoms and medications. It is important for both patients and healthcare providers to pay special attention to managing IH symptoms before, during, and after a procedure. This handout will help you prepare for your upcoming procedure, know what to expect, and understand how the diagnosis of IH can impact your care around the time of the procedure.

Specific considerations for patients with IH include:

- Administration of some IH medications may be delayed due to the timing of the procedure and recovery activities.
- Sedating medications can worsen IH symptoms.
- Patients with IH may be slower to awaken from anesthesia ("delayed emergence").
- Healthcare providers may lack knowledge about IH.
- IH medications may interact with anesthetics.

How can I ensure my IH symptoms are well-controlled before, during, and after anesthesia?

- **Plan in advance** by meeting with your IH healthcare provider to create a strategy for meeting your needs (see "Before Your Procedure," below).
- **Communicate with healthcare providers** at every stage of your treatment. *Be prepared to repeat information to ensure every care provider understands your needs.*
- **Advocate for yourself.** Because IH is not very common, healthcare staff may not be as familiar in caring for your essential needs, particularly around the time of a procedure. You must advocate on your behalf, and bring a friend/family member to your procedure to advocate for you, too.

BEFORE YOUR PROCEDURE

Discuss your procedure with your IH healthcare provider

Well before your procedure, schedule time to talk with your IH healthcare provider and review this Guide. Discuss strategies for coping with IH symptoms before, during, and after the procedure (**periprocedurally**), and how to communicate this information. Create a **Periprocedural Care Plan (see our form⁴)**, which you can present to your various healthcare providers at all stages of your procedure.

By arranging this appointment well in advance, your IH healthcare provider can review your symptoms, order any tests, and make recommendations and provide previous sleep study reports to your procedural team.

Discuss your diagnosis of IH with your team

Your periprocedural team consists of the surgeon, anesthesiologist, and nursing staff. Be sure to notify your team that you have a diagnosis of IH, and discuss your Periprocedural Care Plan.

Make a plan with the anesthesia team

Before the procedure, you will be assessed by the anesthesia doctor/nurse. Because of the unique features of IH, **consider scheduling this meeting well in advance of the procedure**, which may mean a separate appointment. The anesthesia team will help develop your Periprocedural Care Plan. Discuss:

1. The anesthetic plan, including type of anesthetic(s). This will be based on the risks and benefits of using general anesthesia, regional anesthesia, or sedation. If possible, the anesthesiologists can use regional anesthesia (also referred to as a "nerve block") to temporarily anesthetize a particular area of your body so that you do not feel any sensation or pain during the procedure. Nerve blocks may last for a number of hours after the procedure, thereby decreasing the amount of pain and opioid medications needed to control pain and discomfort. This may be beneficial, as opioids can potentially interfere with your sleepiness levels and your recovery from anesthesia. But a regional anesthetic may not be possible with some conditions.
2. That IH medications may interact with anesthetics and IH symptoms may cause a need for different amounts or types of anesthetics to maintain an appropriate depth of anesthesia. Consider depth of anesthesia monitoring and use of shorter-acting anesthetic agents whenever possible.
3. The pain management plan. This plan should attempt to use "multimodal analgesia" (multiple different techniques or types of medications for pain control) in order to minimize the use of opioids, if possible.
4. The possible need for closer-than-usual monitoring, to look for alertness or over-sedation during and after the procedure.

THE DAY OF YOUR PROCEDURE

Most IH medications should be taken as usual for as long as possible before a procedure. This is important not only for controlling your IH symptoms, but also for minimizing any side effects related to re-establishing the dose after your procedure. Make sure to confirm this with your IH healthcare provider and anesthesiologist.

Prepare to bring the following to your surgery:

- **A supply of your prescribed IH medications**, in case the pharmacy cannot get your specific medications to the postoperative care unit. Note: inform your team that you have these medications with you.
- **Your Periprocedural Care Plan and this Guide.** Bring several copies to keep with your chart and to share with the healthcare team and your accompanying family members/friends.

- **Your Hypersomnia Foundation Medical Alert Card⁵**, or any other medical alert of your preference (such as a bracelet or smartphone app).

Review the anesthetic plan

- As discussed above, your procedure may be performed under different types of anesthesia. Review the risks and benefits of each of these options with your anesthesiologist.
- Review your pain management plan with your medical team.

AFTER YOUR PROCEDURE

- Resume your regular medications as advised by your medical team, after careful consideration of possible drug interactions. Your goal should be to resume your usual treatment as soon as possible to avoid worsening of your IH symptoms.
- Remind healthcare providers to review your Perioperative Care Plan, including details such as: 1) your usual response to pain medications, including opioids; 2) the need to avoid sedating medications as much as possible; 3) the need to use alternative medications, if available, if you can't take oral medications; and 4) that sleep deprivation can significantly worsen your IH symptoms.
- Be aware that every time you leave your hospital room for a procedure (such as physical therapy), or transfer to a different clinical area, scheduled doses of your IH medications may be delayed. Discuss this with your healthcare providers **before** your procedure or test so

that all staff knows to give priority consideration to your medication needs.

Review a plan for pain control for after your discharge

Before discharge home, discuss with your healthcare providers any potential medication side effects, such as drowsiness or slowing of breathing from opioids. Discuss any possible drug interactions between new medications and your regular medications. It is important to balance your level of pain control with any possible sedating side effects or drug interactions.

Keep track of your IH symptoms

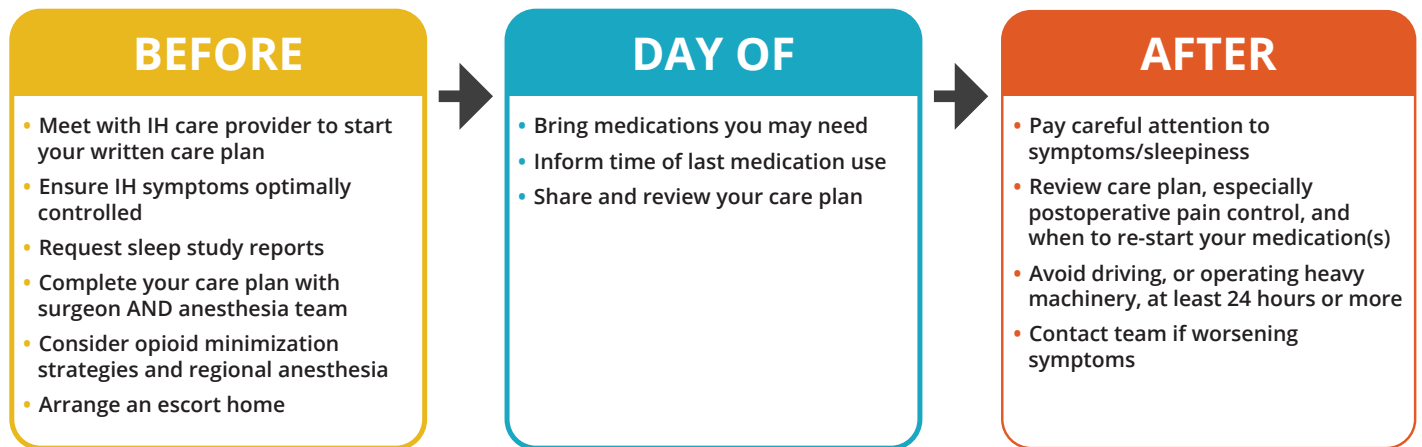
- Pay careful attention to your sleepiness while at the hospital.
- Keep track of your level of sleepiness after discharge home. If your sleepiness worsens, tell your caregivers and doctors, to determine if any medication changes are needed.

Have someone escort you home

If you are going home the same day of your procedure, make sure that you have someone available to escort you home.

Avoid driving or operating heavy machinery

Avoid driving or operating heavy machinery after anesthesia until it is safe to do so. Usual recommendations for all patients are to avoid these activities for at least 24 hours, but patients with IH may need to avoid these activities for even longer. Discuss this issue with your team, as your medications may need to be adjusted before you resume these activities.



References:

1. Aflaki S, Hu S, Kamel RA, Chung F, Singh M. Case report of a patient with idiopathic hypersomnia and a family history of malignant hyperthermia undergoing general anesthesia: An overview of the anesthetic considerations. *Anesthesia & Analgesia Case Reports*. 2017;8(9):238-241.
2. American Academy of Sleep Medicine (AASM). The International Classification of Sleep Disorders - Third Edition (ICSD-3).
3. Billiard M, Sonka K. Idiopathic hypersomnia. *Sleep Med Rev*. 2016;29:23-33.
4. hypersomniafoundation.org/periprocedural-care-plan
5. hypersomniafoundation.org/medical-alert-card
6. **Useful resources for medication information:**
 - a. Medline Plus: medlineplus.gov/druginformation.html
 - b. Thorpy MJ, Dauvilliers Y: Clinical and practical considerations in the pharmacologic management of narcolepsy. *Sleep Med*. 2015;16:9-18.

DISCLAIMER: This Guide is intended for educational purposes only; it is not meant to substitute for medical advice or to be taken as such. Every individual is different, and their medical conditions can vary widely. Please consult your own healthcare professionals before making any decisions regarding your healthcare or your medical management.



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