



## **LIVING WITH IDIOPATHIC HYPERSOMNIA & LIVING WITH NARCOLEPSY COMMUNITY GROUPS**

### **Information and Guidelines for Attendees**

To ensure the aims of our Living with Idiopathic Hypersomnia and Living with Narcolepsy community groups are met, Hypersomnolence Australia has developed guidelines to outline the purpose of the groups and for attendance and participation.

#### **PURPOSE**

Hypersomnolence Australia believes in providing quality support to individuals living with Idiopathic Hypersomnia (IH) and Narcolepsy, and our community groups are a great way to do this. Our groups are a friendly safe environment where members can discuss their challenges and successes as well as share advice, resources, and support. The groups are facilitated by experienced members of the Hypersomnolence Australia team and are designed to reduce social isolation and to provide support and information for people living with IH and Narcolepsy.

#### **DETAILS OF SUPPORT GROUP**

Living with IH (LWIH) and Living with Narcolepsy (LWN) community groups will be run virtually (via Google Meet). There will be from time to time in person meet ups. Information about these meetings will be posted on our social media and [website blog](#).

Both the Neurological & Sleep Associations are "Australasian" therefore our group is open to people living in Australia and New Zealand.

LWIH and LWN support groups will be run regularly (dates/times are subject to change):

#### **LIVING WITH IDIOPATHIC HYPERSOMNIA:**

##### ***3rd Wednesday every month***

4.30pm – AWST

6.30pm\* - AEST

8.30pm – NZ time

#### **LIVING WITH NARCOLEPSY:**

##### ***1st Wednesday every month***

5.30 - AWST

7.30pm\* - AEST

9.30pm – NZ time

*\*Don't forget to add an hour if you live in a state with daylight savings.*

#### **GUIDELINES FOR ATTENDEES**

The following guidelines have been created to ensure the LWIH and LWN purpose is achieved and to give attendees clear expectations. Following these guidelines will ensure all attendees can feel safe to share their experiences, feel connected and gain the most out of the meetings. If you have any questions or concerns regarding the guidelines, please [contact us](#) to discuss this.

- The purpose of the LWIH and LWN communities is to provide an environment for people with IH. Therefore, only people with an Idiopathic Hypersomnia or Narcolepsy diagnosis are permitted to attend our respective meetings. Exceptions to this rule will

be at the discretion of the group facilitators only.

- We occasionally have special meetings where we invited the parents of children (adults or minors) with IH or Narcolepsy so parents are encouraged to register their interest in our meetings. We will contact them when meetings relevant to them have been scheduled.
- If your child is over eighteen years of age their consent will be required prior to your attendance at LWIH meetings.
- The respect and privacy of everyone involved with LWIH and LWN is essential. It is important that everyone that attends our meetings feel safe, heard, supported and their confidentiality is upheld.

The following will help us achieve this:

- All information shared during LWIH and LWN meetings including but not limited to the topics discussed and the people who have attended meetings should not be discussed outside of our meetings. Anyone found to have breached the confidentiality of our meetings will not be permitted to attend future meetings.
- It is important that everyone that attends our meetings can see everyone else's face. Therefore, all attendees must use their camera. Please contact us prior to the meeting if this is an issue for you.
- All individuals should ensure their name is displayed on either their video or via the chat when entering the meeting.
- To reduce background noise please mute yourself when not speaking.
- LWIH and LWN meetings are designed to unite people experiencing IH and Narcolepsy. Individuals' stories, experiences and suggestions are welcome however, when discussing IH or Narcolepsy itself it must be based on sound evidence; that means it needs to reference reputable sources ie: peer reviewed scientific literature. LWIH and LWN meetings are for those with IH and Narcolepsy to find support from others navigating a similar journey and science should be the standard used to answer questions that are relevant to IH and Narcolepsy.
- Please be mindful that we are all travelling different journeys. While there are classic symptoms of IH and Narcolepsy, the way they affect us and our ability to manage them are influenced by many things, including response to medication, level of support, other health issues and environmental factors.
- None of the content discussed in our meetings should be taken as official medical advice. People are free to discuss what works for them, but always be sure to talk to your doctor before implementing anything you hear in our meeting.

**All new attendees are required to register prior to their first meeting.**

[Click here for the Living with IH group](#)

[Click here for the Living with Narcolepsy group](#)

To avoid going over the same topic in our **LWIH meetings** we have put together a list of [frequently asked questions](#). **Please go over this prior to the meeting.**