



# **LIVING WITH IDIOPATHIC HYPERSOMNIA COMMUNITY GROUP**

## **Information and Guidelines for Attendees**

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

### **PURPOSE**

Hypersomnolence Australia aims to reduce social isolation among individuals living with Idiopathic Hypersomnia (IH) by providing a safe and empowering forum where they can share their experiences with people they can relate to.

### **DETAILS OF SUPPORT GROUP**

Living with IH (LWIH) 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 support groups will be run regularly (dates/times are subject to change):

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

4.30pm – AWST

6.30pm\* - AEST

8.30pm - NZ time

\*NSW & VIC add an hour during daylight savings

### **GUIDELINES FOR ATTENDEES**

The following guidelines have been created to ensure the LWIH 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 LWIH community is to provide an environment for people with IH. Therefore, only people with an Idiopathic Hypersomnia diagnosis are permitted to attend our meetings. Exceptions to this rule will be at the discretion of the group facilitators only.
- If there is enough interest we will have special meetings that are aimed at parents of children (adults or minors) with IH 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 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 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 meetings are designed to unite people experiencing IH. Individuals' stories, experiences and suggestions are welcome however, when discussing IH itself it must be based on sound evidence; that means it needs to reference reputable sources ie: peer reviewed scientific literature. LWIH meetings are for those with IH to find support from others navigating a similar journey and science should be the standard used to answer questions that are relevant to IH.
- Please be mindful that we are all travelling different journeys. While IH symptoms are fairly standard across sufferers the way they affect us and our ability to manage them are influenced by many individual things including response to medication, level of support, other health issues and other 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.

To avoid going over the same topic we have put together a list of [frequently asked questions](#).

**Please go over this prior to the meeting.**

**All new attendees are required to fill in a [quick form](#) prior to their first meeting.**

To ensure that we have enough time to send you an invitation (via email) we need your form no later than 24hrs prior to the meeting.