



Sleep Disorders Australia

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LIVING WITH NARCOLEPSY SUPPORT GROUP

Information and Guidelines for Attendees

INTRODUCTION

It is important to understand the difference between support groups and other groups that may gather. Many groups may gather for therapeutic reasons or professional reasons and are usually facilitated by a professional. A peer support meeting is usually facilitated by individuals that are also experiencing the same challenge as the attendees of the group. Peer support groups are not created to provide therapeutic or professional information for attendees, and they are purely for support purposes.

Individuals access peer support groups for various reasons. Whether you are looking to expand your knowledge and understanding, connect with other individuals facing similar challenges, or to feel validated, it is imperative that you have a safe space to do so.

For this reason, and to ensure the aims of our Living with Narcolepsy support group are met, Sleep Disorders Australia has developed this document to outline the purpose of the group and the guidelines for attendance and participation.

PURPOSE

Sleep Disorders Australia (SDA) aims to reduce social isolation among individuals living with Narcolepsy by providing a safe and empowering forum where their experiences can be shared with, understood by, and validated from, people they can relate to.

DETAILS OF SUPPORT GROUP

Living with Narcolepsy (LWN) support groups will be run virtually via Google Meet at the following times:

First Thursday of the month at 7.00pm* AEST
5.00pm AWST

Second Tuesday of the month at 11.00am* AEST
9.00am AWST

*NSW & Vic add an hour during daylight savings

GUIDELINES FOR ATTENDEES

To ensure the purpose of this support group is achieved and all who attend feel connected in a

safe and comfortable environment, we ask all attendees who wish to participate, to meet and follow these guidelines. If you have any questions or concerns regarding the guidelines, please contact facilitators directly to discuss them.

The Guidelines for Attendees are as below:

- The purpose of LWN support group meetings is to support people with narcolepsy. Therefore, only people with a narcolepsy diagnosis are permitted to attend our meetings. Exceptions to this rule will be at the discretion of the group facilitators only.
- From time to time, we will hold meetings for parents of children (adults or minors) with narcolepsy and we encourage you to register your interest if you would like to be contacted when these meetings are scheduled.

Please note: if your child is over eighteen years of age their consent will be required prior to you attending these meetings.

- The respect and privacy of everyone involved with LWN is essential and it is important that all attendees feel safe, heard, supported and their confidentiality is upheld.

To achieve this:

- All information shared during LWN meetings, including but not limited to, the topics discussed and the people who attend meetings should not be discussed outside of our meetings.
- We ask that all attendees use their camera so that everyone can see each other's face. 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.
- If you need to leave the meeting early, please leave a farewell message in the chat rather than interrupt the discussion.
- We encourage individuals to share their stories and experiences and welcome suggestions, however when discussing narcolepsy itself it must be based on sound evidence and referenced from reputable sources ie: peer reviewed scientific literature.
- Please be mindful that we are all travelling different journeys. While there are classic symptoms of 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.