

April 6th, 2014
So Calif RLS/WED Support Group Meeting
Discussion topics
Outbrief

The following materials replicate the exact comments made by actual participants at the above support group meeting. The information provided includes coping strategies that may not have been tested by standard, accepted scientific method. Therefore, we can neither recommend (or condemn) the strategies detailed below.



Discussion output: How does RLS affect your quality of life?

- **Sleep deprivation**
- **Travel avoidance**
- **Personal relationships**
- **Social events**
- **Driving**
- **Physical side effects from medications**
- **Affects social life**
- **Affects work**
- **Causes lifelong sleep problems**
- **Cannot sit through a movie or TV program**
- **Trouble sleeping**
- **Tired the next day and need a nap**
- **Cannot take long car trips**
- **Difficult to be a houseguest**
- **Difficult to read books**
- **Guilty/sympathy**
- **Disbelief by mate, family member, doctor**



Discussion output: How does RLS affect your quality of life? (cont'd)

- **Social life – don't go out**
- **Can't sit long time – limits entertainment**
- **Don't drive for long**
- **Controls dating**
- **Affects friendships - lack of understanding**
- **Can't sleep with mate – negative effect on relationship**
- **Segregation from others**
- **Depression/anxiety/fear of laying down**
- **Deprives motherhood**
- **Ruined marriage/chronic fatigue**
- **Daytime extreme fatigue**
- **Inability to travel**
- **Feeling drugged all day from nighttime medication**
- **Questions your sanity**



Discussion topic: What techniques/ideas help you cope?

Note: Some of the following coping strategies are unverified by scientific investigation.

- **Combination of diet and exercise**
 - nutritional feedback
- **Trial and error with medication**
- **Walking or exercising**
- **Avoiding the situations that bring on RLS**
- **Hitting**
- **Change of medication**
- **Do things that increase brain activity**
- **Regular sleep schedule**
- **Physical activity**
- **Nap**
- **Stand up periodically**
- **Electronic tablet is helpful**
- **Neurontin helps**
- **Methadone (small amount)**
- **Solitaire**
- **Crochet/knit**
- **Hot packs**
- **Shot of Bailey's**
- **Never leave home without medication**
- **Get on hands and knees with pillow for support and wait for medication to work**



**Discussion topic:
What techniques/ideas help you cope?**

- **Take carbidopa/levodopa (25 – 100) in an emergency**
- **Orgasms work for some**
- **Dual lower leg vibrator**
- **Short drive**
- **Hot shower, Jacuzzi, hot tub, spa**
- **Bicycling**
- **Thrash when sitting/lying down**
- **Ice pack (legs hot/body hot/crawling feeling)**
- **Hit thighs**
- **Yoga/Meditation**
- **Rely on mate**
- **Sleep in chair**
- **Humor**
- **Calcium/Vitamin D**