

# Liz's CMT Surgery

DIARY & GUIDE

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BY  
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*What I Wish I Knew &  
What Helped Me the Most*



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# Liz's CMT Foot Surgery Diary

*What I Wish I Knew (and What Helped Me the Most)*

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**Surgeon:** Dr. Glenn Pfeffer of Cedars Sinai

View Dr. Pfeffer's surgery posts on [Instagram](#) and [Facebook](#)

**For a free surgery evaluation and virtual appointment with Dr. Pfeffer, please follow steps on this page.**

*the*

**Note:** This is just my personal experience. I'm not a medical professional—please talk to your doctor for medical advice. I'm sharing this in hopes that it helps someone else feel a little more prepared.



## My backstory:

I was diagnosed with CMT at 12 and had surgery on both feet in high school, about 17 years ago. My right foot really deteriorated from a bad surgery over the years and was inverted. I was doing OK (or so I thought) and was still able to get around and travel. My doctors told me to wait until I couldn't walk to get surgery since I would just continue to deteriorate, but I felt like things could be better.

I did research and met with Dr. Pfeffer before I decided to take the plunge. I had a few women who talked me through everything, which was a huge help. I thought I was getting by before, but now I am able to hike and be active with almost no pain at all! It was so worth it for me!



## Pre-Op: The Countdown Begins

My pre-op appointment was the **day before surgery**, early in the morning, so I had to fly to LA the **day before that**. Don't cut it close!

On **surgery day**, I was scheduled early in the morning since my surgery was very long (about 7 hours, as mine had a complicated revision). Regular surgeries are about 3-4 hours. I went home that afternoon, and the hospital wheeled me out in a chair and handed me crutches (I highly recommend looking into a wheelchair or knee scooter).

I rode in the **back seat with my foot propped up on pillows**—this helped so much.

A support person is **essential**, especially in the first week. Mine helped with meds, meals, late-night bathroom trips, and—maybe most importantly—keeping me company when I was feeling low.

## The First Two Weeks: Rest, Movies & Wet Wipes

Week 1 was a blur of **sleep, TV, and healing**. I brought crafts, books, and headphones so my support person and I could interact and also have time “apart” while still being in the same room. I also stuck to the rules: **no showering** for the first 2 weeks—hello, dry shampoo and body wipes.

By **Week 2**, I **had** to get out of the room (even though the medical team advises against it). I shuffled around the hotel just for fresh air and a mental break. Still, I kept my **foot elevated** as much as humanly possible.

## The Two-Week Milestone: New Cast, Fresh Start

My **post-op appointment** was **two weeks and one day** after surgery (if you go in on a Monday, your follow-up will likely be Tuesday). They removed the first splint and replaced it with a hard cast, took x-rays, and if everything looks good, you can **fly home the same day** (give yourself **plenty** of time—mine took over 2 hours).

## The Healing Timeline (Everyone’s Different)

Here’s how it went for me:

- **Week 8:** Cast #2 came off. New cast + cleared to start putting weight on it.\*
- **Week 10:** Switched to a walking boot—and finally, a **shower!**
- **Week 12:** Regular shoes again. Could also drive again, as it was my right foot!
- **PT:** Started around week 14. Finding a PT with **CMT or neuropathy experience** can be tricky, but it’s worth it.
- **5 months:** Felt **almost** normal.
- **6 months:** Slight discomfort remained (1–2 pain level).
- **12 months:** Others say the pain is completely gone.

\*Generally, you can start weight-bearing at 6 weeks post-op for less complicated procedures.



1<sup>st</sup> Cast/Splint



Nerve block pump



2<sup>nd</sup> Cast



3<sup>rd</sup> cast (weight bearing)





## Travel Tips (Especially for the Trip Home)

- **Extra leg room** is **so** worth it on the way home. I splurged when I got a pop-up upgrade offer from my airline app.
- **Request airport wheelchair service.** It helped me get from check-in to my seat without stress.



## Hotel vs Airbnb: My Experience

I originally booked an Airbnb... but when Dr. Pfeffer said I might need a **wheelchair**, I realized it wasn't accessible. I switched to the **Sheraton Gateway LAX** and was grateful for:

- Restaurant in the building (no cooking needed!)
- Handicap-accessible room near elevator
- Microwave/fridge access
- Room service & grocery delivery
- Extra pillows to elevate my leg
- Bonus: "Club Lounge" access with snacks and breakfast. Ask for upgrades!

**Parking tip:** Our hotel charged \$75/day, but dropped to \$45/day for multiple nights. Ouch.



## What I Packed & What I Bought There

### Packed:

- Loose pants/shorts (for giant splint)
- Activities- coloring books, embroidery, books, playing cards
- Dry shampoo, body wipes, waterless shower cap
- Lap desk (collapsible)
- Roku stick/HDMI cable

- Extension cord & scissors

### Bought in LA:

- Snacks (Cup Noodles, oatmeal, tuna, etc.)
- Paper towels, wipes
- Tylenol, baby aspirin
- Metamucil or Colace (for *those* pain med side effects)

### Bought for Home:

- Shower stool
- Cast cover
- Vitamin D



## Mobility Tools That Actually Helped

The hospital gave me **crutches**, and I also ordered a **knee scooter** (delivered via Amazon to my hotel). In hindsight, I should have rented a wheelchair locally.

**Skip the iWalk**—at least for me, it was a total fail.



## Pain: What It Felt Like (And What Helped)

I had a **nerve block catheter** in my thigh for the first week. It numbed most of my leg, but I still felt pain in the **ankle and arch**, so I took the prescribed meds. A **reminder app** was key for tracking meds in the first 2 weeks.

- After the nerve block wore off, pain peaked around a **6–7 out of 10**, but generally was very manageable and closer to a 3 or so.
- I took Oxycodone at night only after the first week
- **Gabapentin** helped with twitching at night

- Off all meds by week 2 (except the Gabapentin)

## When You Get Back Home

If you don't have a live-in caregiver, make sure someone can stop by daily for food, errands, and **emotional support**. I stocked up on groceries and prepped my space before I left:

- Set up shower stool and cast cover
- Moved things within reach
- Made a cozy couch setup with pillows for foot elevation

## Random But Useful Tips

- Do **not shave or get a pedicure** before surgery. I cut my toe and they ***almost canceled*** the procedure.
- Follow up early with **Darrien** to get your **pre-op checkup form**:  
***Darrien.Sturgis@cshs.org***
- If insurance offers travel stipends, ask **Dr. Pfeffer** for a letter explaining why he's the specialist you need
- **No aspirin or ibuprofen** 10 days before surgery
- **Nothing to eat or drink after midnight** before surgery

## Final Words

This journey was **hard**, but manageable with preparation and support. If you're reading this because you're going through something similar, I hope it brings you a little peace and clarity. It is scary, but it was so worth it! Even my friends and family have comments on my foot and how much better I am walking now- it was life-changing!

And remember—you **will shower again**. 😊

Feel free to reach out if you have questions: [liz.dougherty1@gmail.com](mailto:liz.dougherty1@gmail.com)

**For more CMT resources, visit [hnf-cure.org](http://hnf-cure.org)**