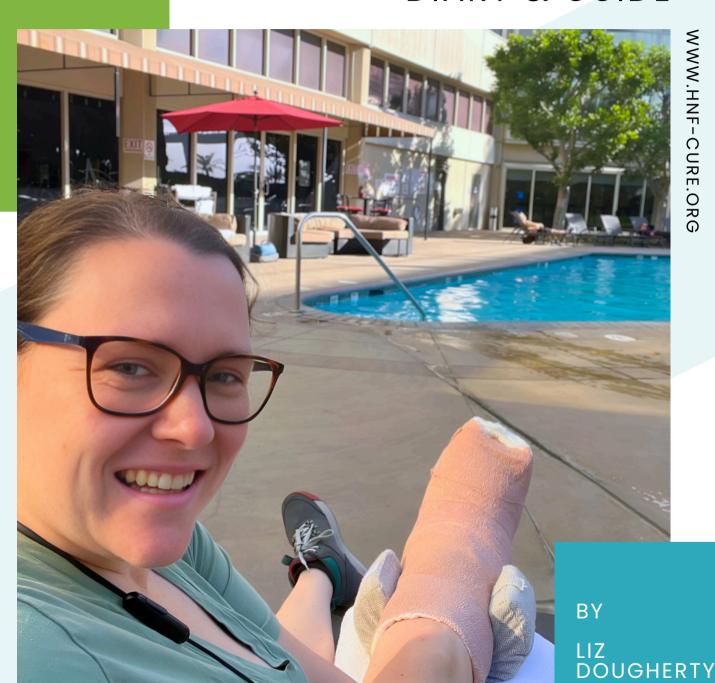
Liz's CMT Surgery

DIARY & GUIDE



What I Wish I Knew & What Helped Me the Most



WWW.HNF-CURE.ORG

WWW.HNF-CURE.ORG



What I Wish I Knew (and What Helped Me the Most)
Liz Dougherty | liz.dougherty1@gmail.com

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).

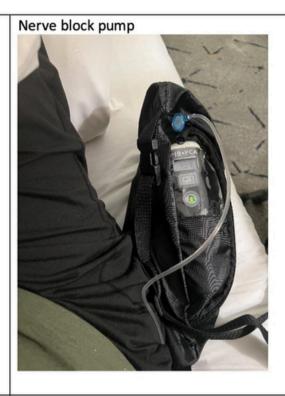
The Healing Timeline (Everyone's Different)

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.









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)



Mhen 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. (2)

Feel free to reach out if you have questions: liz.dougherty1@gmail.com

For more CMT resources, visit hnf-cure.org