

## **Post-Surgery Survival Guide**

Advice for Youth, By Youth

The youth of the CMTA would like to extend the hand of friendship to you, with advice gleaned directly from their own experiences with CMT related surgery.

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Recovery is about more than elevating your foot and taking your meds on time (although both are very important!) - it's also about practicing self care, staying connected and protecting your mental health.

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With this guide, we want you to know that you are never alone in your recovery. You are part of a supportive tribe who have your back and will be here for you every "step" of the way!



## **Recovery Tips!**



"I would recommend reaching out to family and friends as much as possible! After my surgery, I was bored and felt a little lonely being away from people. Talking on the phone or even texting really helped me mentally! It really brightened my day!" - Kaitlin Siegel

"Decide what assistive mobility devices you'll need ahead of time. Plan, plan, plan!" - Laylah Giddens



"Try to get outdoors as much as possible. Once I was given permission from my doctor, I took mini road trips every day and listened to music. A daily dose of fresh air is so important for the soul." - Season Ciriello

"Always research. About everything. The more you learn about CMT, the better you can handle it.

- Connor McBride

"Be patient with yourself. Don't rush your recovery process. I know it is easy to compare your healing process with your friends'. It is important to remind yourself that you are different people, healing at a different pace. Take this process one step at a time. Surround yourself with people and things that bring you joy! Lastly, remind yourself that you are not in this recovery process alone! You got this!" - Riley Williams

"Try and fill your time whilst recovering with activities you enjoy. It's a long, slow process and requires a lot of laying in bed, resting, but that doesn't mean it has to be boring. I learnt to knit, had friends visit and watched A LOT of TV and films." - Elisheva Landau-Pope





Need a TV show to binge? Here are some suggestions from our youth community!

"Gilmore Girls"

"Enola Holmes"

"Amphibia"

"Arcane: League of

Legends"

"The Bachelor"

"SpongeBob SquarePants"

"RuPaul's Drag Race"

"Heartstopper"

## Our friends shared their top must-haves for postsurgery recovery

"Fuzzy socks!" "Puzzles!"

"TV tray!" "Your favorite blanket

from home!"

"Comfy sleep shorts!"

"Snacks!"

"Coloring books!" "Board games!"

"Lots of pillows for "Cast cover for elevation!" showering!"



"Remember your mental and physical strength! Surgery can be hard, but living with CMT every day prepares you for it - it makes you more resilient than the average person. Also, if you ever need to talk to someone about your surgery experience, do not hesitate to reach out to someone on The Youth Council! Many of us have had one or more CMT-related surgeries and would be happy to talk to you about it (or anything else you want to

talk about). You're not alone!" - Jaden Ellman



"Listen to your surgeons and doctors! I am guilty of not following post-operative instructions, and I ended up in more pain and with a longer recovery time. No matter how annoying these rules may seem now, they are so important to follow!" - Lily Sander

"Make physical therapy your number one priority after recovery. Strengthening is just as important as the surgery itself." -Season Ciriello

"If you can, invest in an adjustable bed backrest to use behind pillows so you can sit up in bed comfortably, as well as a table that can fit over you in bed. This is especially helpful for the first couple weeks after, when you might not have the energy to get up to sit in a chair."- Elisheva Landau-Pope

"Have a family "Face masks!" movie night!"

"Video chat loved ones!"

"Study!"

Bored on the couch?

Here are some non-weightbearing activity ideas from other youth!

"Read anything and everything!"

"Listen to podcasts!"

"Use coloring books!"

We wish you the best during your recovery!

Remember that you are not alone, and on behalf of the CMTA Youth Tribe, we are here for you every step of the way.

Whether you need advice, a friend to vent to, or just a good chat with someone who gets it, there is always someone just a message away in our youth database!

You are strong, and you've got this!

## Stay connected!



Follow
@cmtayouth on
Instagram and
Facebook

★ Sign up for our
Youth Database!



Contact our National Youth Programs
Manager, Jonah Berger, with any
questions!

Email: Jonah@cmtausa.org