General Rehab Patient Guidelines After Tethered Cord Release

It's important to first understand that there is no fixed timeline and everyone adjusts differently after surgery for Tethered Cord Syndrome, especially if you have a connective tissue disorder (like EDS or related conditions). This document outlines phases of recovery that are often experienced and perceived by the provider and the patient in the first 3 to 6 months post surgery. Your recovery process may be different, and should be guided by your surgeon and physical therapist. Progress is based on how your body responds, not on a strict timeline. Even slow progress is progress. Flare-ups can still occur, especially in those with more sensitized nervous systems, and be disconcerting for the patient. This may be more likely to occur in the first few months after the surgery. *This handout is for education and does not replace medical advice.*

Overall Approach

The Big Goals

1. Go slow and stop if any activity worsens your symptoms
2. Calm your nervous system with breathing or grounding exercises
3. Build stability before you work on flexibility or big movements
4. Focus is on form, not intensity of the exercise

Cautions

- Aggressive stretching
- Heavy resistance at end-range positions (pushing joints or your spine to your limit)
- Pushing through pain, fatigue, or numbness/tingling/increased pain
- Traditional strengthening exercises before you are able to find good alignment
- High-repetitions or exhausting workouts
- Progressing too quickly – you shouldn't increase the intensity of the exercise until you can do the lower level exercises without increasing symptoms (numbness/tingling/increased pain)
- Bent, twisted, or end-range positions
- Don't rely ***only*** on passive symptom relief. You will need to simultaneously be rebuilding control

Goals

- Progress based on symptoms, not the calendar
- Use short, frequent sessions instead of long sessions
- Use neutral alignment (this is important to learn what it feels like with a rehab therapist)
- Work on diaphragmatic breathing
- Choose supported positions (pillows, bolsters, lying down options) to encourage a neutral spine position
- Focus on gentle engagement and control
- Watch for delayed reactions later that day or the next day (pain, fatigue, worsening nerve symptoms)
- Report changes in your symptoms to your medical provider, then gradually learn how to adjust activity yourself to prevent the flares

Important: Recovery isn't always a straight line. If you flare, you may need to step back to an earlier phase for a while.

Phases of recovery

1) Early Phase: Protection & Regulation

Goal: Calm the system, protect healing tissues, and reduce irritation.

- Prioritize rest, comfortable and supported positions, and symptom control
- Avoid stretching or "pushing mobility" early on
- Focus on neutral alignment in all positions (lying down, sitting, standing)
- Most of your activity will be for essential daily tasks (bathing, dressing, toileting, feeding), don't push to do more than that
- Start gentle breathing and nervous system calming strategies; focusing on the exhale may help stimulate parasympathetic activity
- Report any worsening of your symptoms to your medical provider

Key ideas: *Less is more. Do not provoke symptoms.*

Focus on controlling inflammatory responses and neural sensitivity with your medical team.

---

2) Alignment, Stabilization & Awareness Phase

Goal: Rebuild control, alignment, and body awareness (proprioception)

- This is not strengthening, but activation of the muscles to be able to safely work into strengthening
- Begin gentle activation of your deep stabilizing muscles (transverse abdominus, multifidi, hip rotators, deep neck flexors)
- Practice good alignment in all positions (lying down, sitting, standing, walking)
- Keep movement low-load and the body supported
- Increase activity to include walking as tolerated
- Move enough to handle most daily tasks
- Continue to avoid end-range strain or loading
- Report any worsening of your symptoms to your medical provider

Key ideas: *Find alignment first, then add movement later.*

Muscle activation before strengthening.

Learn safe pacing for optimal recovery.

---

3) Controlled Movement Phase

Goal: Safely add coordinated and functional movements

- Start light functional tasks as tolerated (focus on spinal position and hip hinging with your rehab team)
- Keep the focus on movement quality, not quantity
- Gradually increase time upright and walking distance
- Be alert for changes that could indicate nerve irritation or an inflammatory flare-up.
- Report any worsening of your symptoms to your medical provider

Key ideas: *Go slowly and watch for delayed symptom responses ("next day pain").*

Slowly start working on neural mobility with your provider.

---

4) Progression Phase: Function & Endurance

Goal: Build stamina and return to higher-level function as your body allows

- Gradually increase activity tolerance and endurance
- Add more complex movement patterns when appropriate
- Keep prioritizing alignment and symptom monitoring

Key ideas: *Function builds on a stable foundation.*

Master pacing.

Important considerations

1. Recovery can be unpredictable.
2. Setbacks can happen and provide useful information for how to adjust.
3. Flare-ups (pain, fatigue, neurological symptoms) usually mean you should step back to an earlier phase until you can tolerate that phase without provoking symptoms. This may require close attention to general inflammation, immune system, or MCAS related responses from the medical team.
4. Avoid aggressive or traditional strengthening early, especially if you are hypermobile. Proper alignment is first, then add muscle activation and control, which is needed before strengthening.
5. Ongoing communication with your therapist is important, especially at the beginning.