



Cushing's Post-Treatment Tips

You've completed your treatment and you're now on the "road to recovery". This is a time when peer support from other patients becomes especially helpful because there isn't a lot of deep detail in the literature yet. CSRFB has been collecting this exact data for years in surveys designed by teams of patients. Links to some of these study materials can be found below.

- Set expectations. Journaling can help your mind and spirit. You will start to see improvements over the weeks and months, not days. Some items to track could be your weight, length of walks, ability to climb stairs, improved stamina on tasks, etc. Many feel that healing begins after you have tapered off steroids.
- Anticipate decreased muscle mass, strength, energy levels and fatigue along with increased joint and body pain - stretching and yoga could be very helpful. Consider joining an exercise group or working with a physical therapist or trainer to help address specific weaknesses. Epsom salt baths can be comforting. Rest, rest and more rest.
- Work at your own pace. Break up chores and errands.
- Mental health is extremely important. Depression, apathy and impaired memory issues are common. A support group and talking with other Cushing's patients can be a lifeline.
- Be mindful of your general health as your immune system may be impaired. Pace yourself, ask for help and advocate for yourself during your medical appointments. Don't be afraid to tell your doctor about changes you feel happening with your mind or body.
- Keep a sense of humor and understand that "it WILL get better" with time. Celebrate all the small victories!
- If you have temporary or permanent adrenal insufficiency (AI), it's important that you understand the relationship between lab results, steroid replacement and how you feel, so you can administer stress dosing and recognize signs of crisis.
- If you have AI, wear a medical alert bracelet while on steroid replacement.

Over time your loved one will recover from most of the effects of Cushing's, but we are changed by this experience. Healthy, open communication can lead to new connections and healthier long-term outlooks. Your role in helping the one you love is enormous. How are you holding up? We've included a thoughtful resource below for you as well.



SCAN FOR LINKS

- Cushing's Support and Research Foundation website: <https://csrf.net/>
- Leslie Edwin, President: leslie@csrf.net - Gretchen Jordan, Associate Director: gretchen@csrf.net
- National Alliance for Caregiving Rare Report: <https://www.caregiving.org/rare/>
- CSRFB Monthly Support Zoom Sign-Up: <https://www.surveymonkey.com/r/2024CSRFBsupportcalls>
- CSRFB Member Quality of Life Survey Report: <https://csrf.net/reportsandpresentations/>

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