



LIVING WITH A RARE KIDNEY DISEASE

There are a lot of emotions that may come with living with a rare disease like C3G. You may experience uncertainty regarding changes in lab results, disease progression, and anticipation of what lies ahead. It can be challenging to find the right words to express these emotions. Do not forget that you have the strength to handle both your diagnosis and your feelings. If these feelings persist, it is advisable to get professional help.

Taking these suggestions into account can help you monitor how your body is doing.

Consider contacting a mental health doctor or practitioner for additional information and support.



FIND OTHERS WITH C3G

Speak to someone who is going through a similar experience. Their advice, guidance, and assurance can be invaluable. Connecting with online communities or patient support groups is a great place to start.



ACCEPT HELP WHEN YOU NEED IT

You don't have to do everything yourself. Whenever possible, accept help from friends and family members.



TRY JOURNALING

Dedicate 15 minutes to jotting down whatever comes to mind. Writing can anchor you when things feel out of control.



TRY THESE TIPS IF YOU HAVE TROUBLE SLEEPING

- When your sleep becomes irregular, don't be too hard on yourself
- To get enough sleep, you may need to go to bed earlier at night or stay in bed later in the morning
- Consider taking a daytime nap to make up for lost sleep



TRY BREATHING EXERCISES AND MEDITATION

Deep breathing can calm you quickly when you feel overwhelmed:

- Sit somewhere comfy
- · Focus on your breath
- Inhale through your nose for 10 seconds
- Hold your breath for 10 seconds
- Exhale through your mouth for 10 seconds
- Repeat this cycle 10 times: Start by repeating a few times and gradually increase the duration

Meditation promotes mindfulness and can help reduce stress.



REAP THE BENEFITS OF EXERCISE



EASE IN WITH MICRO WORKOUTS

- Exercising regularly can help you focus on the present, but it can also help reduce stress and improve self-confidence. Plus, it releases "feel good" endorphins
- Do full-body workouts like dancing or skipping rope in the comfort of your living room while you jam out to your favorite music
- Sign up for a scheduled activity like a yoga session or dance class



BE OUTDOORS

Being outdoors can be challenging when living with fatigue. Here are some tips to make it easier:

- Keep comfortable shoes, coats, and mobility aids close at hand in your entryway
- A patio or rooftop terrace or a stroll around the block can still expose you to fresh air and sun



FIND A FITNESS PARTNER

Doing activities together can help you feel supported and motivated while you're having fun.

IMPORTANT: PLEASE CONSULT YOUR DOCTOR BEFORE

STARTING ANY NEW EXERCISE REGIMEN



DO THINGS YOU ENJOY



PUT SOMETHING ON THE CALENDAR

Give yourself something to look forward to by scheduling a trip, activity, or event in the next few months. Putting it on the calendar will give you a solid plan. Remember, it's okay to cancel plans and stay home on days when you don't feel like leaving.



SPEND TIME WITH OTHERS

Hang with friends, date, plan a group trip. Having C3G doesn't mean you have to put your life on hold.



HEALTHY FOOD CHOICES ARE HAPPY FOOD CHOICES

When you nourish your body with good food, you feel better. If you want to try kidney-friendly foods, you can talk to a nutritionist.



TAP INTO YOUR CREATIVE SIDE

You can add extra joy to your life by engaging in creative activities like gardening, baking, painting, making videos, and creating crafts.



Coping with C3G can have its moments of ups and downs. We hope this guide helps you nurture both your mental and physical well-being. While it is possible that you may need to try several times to find the optimal approach for you, these tips can help set you on the right path. You've got this.

Patient portrayal.



SOME WAYS CAREGIVERS CAN HELP

Caring for someone with C3G can be a challenge. It is important to provide them with the support they need in order to successfully cope with change and manage all the new experiences they will encounter.



HERE ARE SOME TIPS TO HELP:

- Finding the right way to explain your loved one's diagnosis to them can be difficult. Explore metaphors and simplified language to make it easier for them to comprehend
- Coping with bodily transformation during adolescence can be challenging for all, yet it
 may be even more daunting for patients dealing with rare kidney disease. Encourage
 your loved one to open up about their worries and emotions concerning this transition
- Remember to acknowledge your loved one's efforts when they follow instructions or take part in therapy
- Encourage them to write down any questions they have about their disease
- Encourage your loved one to familiarize themselves with the names and dosing regimens of their medicines
- If you or your loved one are experiencing troubling emotional states, it is recommended to seek professional assistance from a mental health expert



EXPLORE EVEN MORE C3G RESOURCES

AND SUPPORT AT KIDNEYHOPE.COM

All trademarks are the property of their respective owners.

