Caring for a loved one with C3G

Use this guide to help you care for a loved one with C3G.
Inside you'll find advice about providing care as well as resources to help you along the way.







Take your care further

We recognize that caregivers are silent heroes and can sometimes use a bit of support too. So whether you're a parent, family member, partner, or friend, this guide offers you advice on how to provide ongoing care for someone with C3G.

C3G is a rare condition that affects how well a person's kidneys work. It may impact your loved one's mindset, schedule, and lifestyle—so being able to lean on a caregiver for support can be crucial.



It's important to remember that as your loved one's condition changes over time, so will the way you provide care.



Support starts with you

Every situation is different, and C3G may present different physical and emotional challenges for each patient and caregiver. Regardless of the situation, here are some helpful tips to consider as you begin this caregiving journey.

Ways to begin your journey as a caregiver



Educate yourself

The emotional rollercoaster of diagnosis, potential disease progression, and lack of treatment options can be overwhelming. By becoming informed and aware of all aspects of C3G, you can help reassure your loved one that things will be ok.



Stay positive

Bring your voice to the table as a calming and comforting influence. There may be ups and downs with C3G but your support should remain constant. On tough days, it's important to stay positive and remind your loved one that you're there for them.



Communicate openly

It is common for those diagnosed to suffer from anxiety and struggle with their mental health. This can impact their diet, exercise, social life, and well-being. Periodically ask them if they need anything and let them know you will listen to their struggles without judgment.



Keep daily tasks manageable

It can be overwhelming to try and accomplish too much at once. Make a checklist of 2 to 3 tasks for the day. Consider simple things you and your loved one want to get done such as eating healthy or exercising.



Tap into the caregiver community

Caregivers often find comfort in forums where they can meet and speak with others who carry the same responsibilities. Nonprofit organizations such as the National Kidney Foundation (<u>kidney.org</u>) and NORD (rarediseases.org) are great places to find education resources.



Your self care is key to their health care

Managing your own life, career, and schedule can be overwhelming when you're trying to care for someone with C3G. Here are some things you can do to help you take care of your own mental and physical health.



Focus on family

Family can be a great source of energy. Having family dinners and finding fun activities to do when you're all together can be a great way to bond and re-energize yourself.

If you're a parent with more than one child, ensure that you set aside time for each of them so they feel loved and included.



Spend time with friends

Whether it's grabbing lunch, coffee, or even just a phone call, these moments allow you the space to talk freely and decompress. They can be a great source of comfort and help you recharge your batteries.



Explore hobbies and interests

A C3G diagnosis doesn't mean you have to put everything else on hold. Ensuring that you give yourself the time and space that you need for your own enjoyment can help you feel refreshed.



Establish a support system

Caregiving shouldn't fall on one person. Talk to others in your world about how they can help. This can include driving your loved one to appointments, picking up their medications, or planning fun activities.



Support and resources for you and your loved one

As a caregiver, you're not alone and there are lots of great resources and organizations available to support you. Here are two resources to help you take an active role in your loved one's C3G.



Commonly used terms in C3G

This useful glossary provides an overview of C3G, what different terms mean, and how to help manage this condition.





Productive Appointments Guide

Make the most of your loved one's appointments by being prepared and learning what to ask for.





Join Kidney Hope

Scan this QR code or sign up on <u>Kidneyhope.com</u> to learn more about caring for someone with C3G. Here, you'll find ongoing information, tools, and resources to help you along your journey.



FIND C3G RESOURCES AND SUPPORT

KIDNEYHOPE.COM HAS LOTS OF GREAT INFORMATION TO HELP YOU OR YOUR LOVED ONE LEARN MORE ABOUT C3G, GET EDUCATIONAL RESOURCES, AND FIND SUPPORT.



