ONLINE Support Group

Week 4: Managing the Rollercoaster

Welcome to the Crohn’s & Colitis Foundation’s Online Support Group for Caregivers

Managing the ups-and-downs of inflammatory bowel disease (IBD) can often feel like a roller coaster – for your loved one as well as yourself. There may be times when your loved one’s disease is under control, and times when it is not. And, it may take some time to adjust, which is completely normal.

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Since IBD is a life-long condition, it is important that you set yourself up for success – be prepared, pace yourself, and find the support that you need. But, most importantly, make sure you are taking care of yourself. Remember…this is a marathon, not a sprint!

Below, you will find some tips and strategies to help you along your caregiver journey.

8 Tips for Caregiver Success

1. **Educate yourself about inflammatory bowel disease.** *Knowledge is power.*
2. **Get organized.** *Plan ahead and be prepared.*
3. **Be an advocate for your loved one.** *Stand up for their rights.*
4. **Connect with other caregivers.** *It’s helpful to talk to others who know exactly what you’re going through.*
5. **Take care of yourself.** *You can’t be there for others if you are not there for yourself.*
6. **Pace yourself.** *Slow and steady wins the race.*
7. **Give yourself a break.** *Don’t burn yourself out.*
8. **Rely on others.** *Ask for help when you need it, and accept it when it’s offered.*

Educate yourself about inflammatory bowel disease

The more informed you are about your loved one’s Crohn’s or colitis, the better you can assist them manage their disease.   However, the amount of information out there about Crohn’s and colitis can be overwhelming. Start with one resource, such as one of the Crohn’s & Colitis Foundation’s webcasts or brochures, and slowly read or view additional resources over time. You won't become an expert overnight, but you'll learn more and more as time goes by.

When seeking information online, make sure it comes from a trusted source – not all message boards, blogs, and websites contain high-quality or accurate information. If you have a medical question, it is best to talk about it with your medical team. The Foundation's IBD Help Center is also here to help!

Tip

- Check out the Crohn's & Colitis Foundation website to access videos, webcasts, brochures, and fact sheets covering a variety of topics – www.crohnscolitisfoundation.org

Get organized

One way to help ease stress is by planning ahead and staying organized. Something unexpected or out of your control will always come up. Therefore, when you can, it is important to plan out those things that you can control. Organizing yourself now, can help reduce the number of things you need to take care of in the future, giving you more energy to deal with those unexpected events when they come up.

One event that you need to be prepared for is your loved one's doctor visit. When you are accompanying your loved one to a doctor's appointment, you may feel pressured to get all of your questions answered in a short period of time. Writing down your questions ahead of time will be helpful. You will also want to prioritize your questions, ensuring that the most pressing issues are addressed first. If you don't understand something, ask the doctor to clarify. If the appointment is over and you feel like you still haven't gotten your questions answered, ask the doctor about scheduling a follow-up appointment (also known as a consultation) or talking to a nurse on staff. Some doctors may also feel comfortable providing information via e-mail. Don't be afraid to ask questions!

Tips

- Get a special calendar to make down your loved one's appointments and medication schedule.
- Prior to your loved one's doctor visit, write down your loved one's symptoms and behaviors – such as number of bowel movements, eating behaviors, emotional state, and whether they are taking their medications – and how often they happen. The more detail you have, the easier it is for the doctor to provide the best possible treatment. Contact the Crohn's & Colitis Foundation to find various symptom trackers.

Be an advocate

As a caregiver, you are a wonderful source of support for your loved one. At times (especially for pediatric and elderly patients), you may need to take on a larger role and become your loved one's advocate. For example, making sure your loved one has access to appropriate medical care or that your child has special accommodations in school.

Tips

- *If your loved one is not willing or able to make decisions, make sure that you go with your loved one to their doctor appointments so that you can hear what the doctor is saying and can ask questions. If this is the case, be sure to let the doctor know why you are there and what your role is. (If necessary, you can also talk to your loved one about creating health care proxy and power of attorney documents.)*

- *There are a variety of resources out there that you may not know about – don't hesitate to ask your loved one's healthcare team or the Foundation to help you find them. Staff can direct you to resources such as help paying for medications, finding a psychologist or psychiatrist with expertise in Crohn's or colitis, and setting up a 504 plan (school accommodations) for your child.*
- *You have the right to switch doctors at any point. If you feel that your loved one's doctor is not a good fit, feel free to find another doctor at that facility or outside of that facility.*

Connect with other caregivers

Connecting with other caregivers is vital. At times, being a caregiver can be draining or isolating. You may feel like your closest family members and friends cannot relate to what you are going through. Talking with a fellow caregiver, who may understand the difficulties you are experiencing, be a sympathetic listener, and have advice to offer, can be helpful. Knowing that you are not alone or the only person who feels this way can be relieving and empowering.

Tips

- You have already taken the first step by attending this online support group!
- If you would like to continue speaking with other caregivers:
  - Contact your local Crohn's & Colitis Foundation chapter to see if they currently have an in-person support group for caregivers, or
  - Check out the Foundation's Power of Two (peer-to-peer mentoring) program where you can speak with another caregiver one-on-one.

Take care of yourself

Being a caregiver can be a consuming role. It is easy to put your loved one's needs first, forgetting your own needs. This can do more harm than good in the long-run, causing you to burn out. You cannot be there for your loved one if you neglect yourself. It is important to find an outlet for your feelings and stress, especially when a patient may be newly diagnosed or experiencing a flare. The best thing you can do as a caregiver is to make sure **YOU** are in the best possible health.

Top 10 Caregiver Tips for Staying Healthy and Active (from the American Heart Association)

1. **Get regular physical activity.** Regular, moderate-to-vigorous physical activity is a good energizer that reduces stress, helps keep blood pressure and cholesterol at heart-healthy levels and helps maintain a healthy weight. Aim for 30 minutes a day most days of the week – all days would be best. You can break it down to 10 to 15 minute sessions. Walking is a great way to get started, even if you only walk around the yard.

2. **Eat heart-healthy foods.** They give you more energy, keep your brain fed (which helps combat depression), and help prevent other health problems. If you've got to "eat on the run," choose nutritious snacks.

3. **Take time every day for an activity that you enjoy** such as reading, listening to music, crafts, cooking – whatever makes you happy and relaxes you.

4. **Keep humor in your life.** Laughter is good medicine. Laughing quickens the pulse rate, stimulates the blood circulation, activates muscles, increases oxygen intake and helps you relax. If you've forgotten how to laugh, try to be around people who still know how. Laughing is contagious!

5. **Get out once a week and go somewhere enjoyable.** Visit the local coffee shop, attend church events, take a class, visit a friend, or just wander around the mall or a park. If your loved one needs constant attention, ask for help. You can find someone to give an hour a week to let you get out.

6. **Treat depression and stress.** Recognize signs and symptoms and do something about it as soon as it starts. If you think you may be depressed, get professional help. Talk it out. Admit your feelings.

7. **Take care of your business.** Keep your checkbook balanced, work when you need to, spend time with friends and family, and don't stop planning for the future. It's out there waiting for you. If you live totally in the moment of your caregiver responsibilities, you'll find it more difficult to re-integrate into life later on. Keep living.

8. **Keep all your medical and dental appointments.** Do all you can to keep from getting sick. If you're sick, you won't be able to do what your loved one needs. Ask for help when you need it to get away and take care of your health.

9. **Think positive.** Take time every day to refresh your mind. Admit your limitations. Let go of guilt. Admit that you're angry. Pat yourself on the back for the job you're doing. If you're feeling guilty or angry, take a break.

10. **Stay connected with the outside world, even if it's just by phone or online.** Don't isolate yourself. Talk to friends about something other than your situation. Stay interested in what would be going on in your life if you weren't caregiving. It's still there and you're still a part of it.

Pace yourself

Crohn's and colitis are life-long conditions. Therefore, as a caregiver, if you don't pace yourself, you are going to burn out quickly. While you can't control the fact that your loved one has Crohn's or colitis, you can control how you respond. Acknowledging that it may be a long-term job is a helpful first-step because it gives you the opportunity to plan ahead and find the help that you need. The earlier you learn the art of pacing yourself and asking for help, the easier it will be for you to care for your loved one.

Tips

- There are a lot of things that you will not be able to control about your loved one's disease – focus your efforts on those things that you can control.
- Take it one day at a time – don't let worry about the future take over your ability to care for your loved one today.
- Set your pace for a long race.

Give yourself a break

You are doing a very difficult job, so don't be so hard on yourself. It is normal to feel sad, frustrated, or angry at times. After all, you are only human and doing the best you can to help your loved one. If you notice that you are feeling strongly, it may be helpful to step back and explore the feeling further. Are you feeling alone? Perhaps connecting with another caregiver may be helpful. Are you feeling like you are losing yourself by focusing all of your attention on the patient? Do something for yourself and remember that you are important.

Tips

- Remember to be good to yourself, and cut yourself some slack.
- If you are having difficulty controlling your feelings, seek help from a trained professional, like a psychologist, psychiatrist, or counselor.

Rely on others

Having a support system in place is important. It is also important to share your responsibilities with others, if they are available. Having a team of caregivers will only make it easier on you and your loved one. Are there other friends or family members who can pitch in and take something off of your plate? If so, let them. Connect with other patients and caregivers. Some caregivers find it helpful to seek support from a mental health professional. Exploring what resources are available in your community may be helpful.

Tips

- Don't be afraid to ask for help – it's a sign of maturity not weakness. Speak up when you need it.
- When someone offers to help, accept the offer and give them something specific to do – cook a meal, drive to doctor appointments, or watch your loved one while you take a break.

You will find your own way to cope but please remember **YOU ARE NOT ALONE!**

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This week's online support group

We hope this introduction has been informative. In preparation for this week's live online support group session, consider the following:

- What did you learn from this information?
- What do you still want to learn?
- Do you have any fears or concerns regarding the roller coaster?

To join this week's support group, visit: http://ccfacommunity.org/chatseries.aspx

Crohn's & Colitis Foundation Resources

The Crohn's & Colitis Foundation offers many resources and services to provide you with accurate and current disease-related information. Check out the resources below for more information on living well with IBD:

- The Foundation's **IBD Help Center** is a support line for IBD patients and caregivers. We can help guide you in the right direction—whether you need to locate a doctor, find financial resources, or have questions about the disease. Specialists are available Monday-Friday, 9 AM to 5 PM Eastern Standard Time (EST). Call 1-888-MY-GUT-PAIN (1-888-694-8872) or email info@ccfa.org.

- The Foundation's **Website** (www.crohnscolitisfoundation.org) is a great place to continue your research on IBD. Additionally, you can:
  - View free educational videos and webcasts

  - Download free brochures and fact sheets
  - Connect with your local chapter
  - Find ways to get involved