

# 10 Tips for IgAN Caregivers and Care Partners

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When someone you love is suffering, it's common to suffer along with them. For caregivers and care partners of those diagnosed with IgA Nephropathy (IgAN), it's no different.

While it's an amazing gift to be able to support a loved one, over time it can take a toll, showing up as anxiety and worry, feeling isolated perhaps, helpless and overwhelmed too. It can even ramp up to feeling depressed.

The good news is there are steps you can take to stay ahead of it, and it's important that you do. Because, whether it's your child, partner, other family member or close friend that has IgAN, caring for them starts with caring for yourself. Like the oxygen mask or the life vest on a plane, you must secure yours first before you can begin to help anyone else. Here's what you can do:

## Causes of caregiver/ care partner stress

- Fear
- Helplessness
- Remorse
- Feeling inadequate or ill-prepared
- Feeling overwhelmed
- Feeling isolated and alone
- Unrealistic expectations

### 1. Learn about IgAN.



You can't possibly be in your loved one's shoes, but you can learn about what they are experiencing. And the more you know about what they are going through, the better you will manage your fear for their future and your feelings of helplessness. Plus, the more you will be able to step back, ask informed questions, and deal with real challenges versus imagined ones. But try not to go too heavy into "fix it" mode. Listen to your loved one and their needs and wishes.

### 2. Carve out time for yourself each day.



...even if it's just 15 minutes. Schedule it, honor it and do something you enjoy, whether it's reading a book, watching a favorite show, cranking the tunes, catching up with a friend, or doing something creative.

### 3. Cultivate hope.

Your ability to maintain and radiate hope – and the positivity that comes with it – is key to staying calm and coping in situations that can be scary, confusing or overwhelming. When you are hopeful, you are more resilient and helpful to the person you are caring for—hope is contagious. Develop and nurture hope by:



- Meditating and setting an intention (what you are hoping to get out of the practice before you start)
- Visiting a favorite place that fills you with wonder and a sense of peace
- Speaking with someone supportive who will hear you out without judgment or uninvited advice – join our monthly caregiver support call or consider talking with a counselor
- Journaling, writing down something you are grateful for at the end of each day
- Keeping a healthy sense of humor



#### **4. Boost your feel-good hormones with regular physical activity.**

Exercise is a great stress buster. You don't have to belong to a gym or run a marathon. A brisk walk and stretching counts! It's all about moving your body more!



#### **5. Meditate.**

Meditation supports your physical and emotional health by helping you stay calm and focused on solving the problems before you, not what you fear might happen. Check out our IgAN Mindful Moments at [igan.org](http://igan.org).



#### **6. Talk it out.**

Supporting someone with IgAN can feel very isolating, especially when the person you're caring for lashes out at you, which can happen. There are counselors, support groups and individuals who are also IgAN caregivers standing by in person and online, ready to listen to your concerns and frustrations. You are not alone.



#### **7. Practice acceptance.**

Acceptance frees you from the remorse and frustration you may be feeling over the changes IgAN has brought to your life and to the life of the person you are caring for. Acceptance, coupled with self-forgiveness, also releases you from trying to do it all and feeling inadequate when you can't, clearing the way for you to ask for help when you need it. Acceptance can also help you face the unknowns of IgAN.



#### **8. Ask for help.**

Don't try to go it alone. When you ask for help, you give someone else the chance to feel good about lending a hand and you'll deepen your connection in the process.



#### **9. Know there will be changes to family dynamics.**

Chronic medical conditions inevitably add stress to families, even among the well members who have not been diagnosed. Talk openly, listen and ask questions without judgment if you feel tension, before blow ups if possible. Use it as an opportunity to grow closer.



#### **10. Pay attention to your health.**

This means keeping up with your own health visits and screenings, eating well (a low-fat diet heavy on fruits, vegetables and lean proteins, and low on fried and processed foods), limiting how much alcohol you drink, consuming plenty of water and getting enough sleep (aim for 7 to 8 hours per night).

When thinking about yourself and your role as a caregiver, have you had any of the below in the past year? (Check all that apply)

### Caregiver Stress

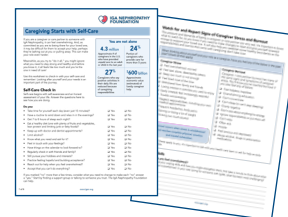
- Feel overwhelmed, worried
- Feel sad, alone, deserted by others
- Sleep too much or not enough
- Feel tired most of the time
- Withdrawal from family and friends
- Losing interest in activities you used to enjoy
- Easily irritated; feel increasingly resentful
- Trouble concentrating
- Neglect responsibilities, including your own medical appointments
- Frequent headaches, body pains
- Gaining or losing a lot of weight
- Drinking too much alcohol

### Caregiver Burnout

Caregiver / care partner burnout has many of the same signs and symptoms of caregiver stress. You'll know you've reached burnout if you also feel any of below:

- Feel helpless, hopeless
- Overwhelming exhaustion
- Can't concentrate
- Can't sleep (or can't stop sleeping)
- Overly negative
- Don't care about anything/no energy
- Ignore responsibilities or put them off
- Can't relax
- Often sick
- Hostile
- Feel anxious and depressed
- Abuse alcohol, drugs or prescription medications

Use our *Caregiver/Care Partner Self-Care check-in worksheet* to reflect on how taking care of or supporting a loved one with IgAN is affecting you. Ask for help if you need it.



## Find support and stay connected

Start with the IgA Nephropathy Foundation's monthly Caregiver/Care Partner Support Group. For more information, visit [igan.org/peer-support-resources](http://igan.org/peer-support-resources). Here you will also be able to:

- Sign up to receive our monthly newsletters
- Access IgAN Mindful Moments for guided meditations and other resources
- Listen to our *IgAN Journey* podcast
- And much more!

Other organizations that offer additional caregiver support and resources:

- Family Caregiver Alliance, [caregiver.org](http://caregiver.org)
- Caregiver Action Network, [caregiveraction.org](http://caregiveraction.org)

