

Practicing Self-care as Caregivers

Avram & Monica, caregivers • 5 minute read



Keep in mind that Hunter syndrome affects everyone differently. These stories do not reflect all the possible experiences that someone may have with this condition. Also remember that your healthcare team will always be your best source of information.

Avram and Monica are many things to each other. They are best friends, soul mates, and loving parents to 3 wonderful children. They are also caregivers of their oldest son, Kalel, who is living with Hunter syndrome. Their day-to-day life can have many ups and downs, but Monica and Avram have learned how to find balance while also finding time to take care of themselves. Together, they share their experiences on how they work together to set boundaries while still maintaining a strong family bond.

Working with each other



Avram and Monica have learned that life with Kael can sometimes feel a little chaotic and, depending on his behavior or mood, unpredictable. Some days Kael is making a mess in the house. Other days, Avram and Monica find it hard to help Kael get all of his energy out. And they're not just focused on taking care of Kael—they are also caring for their 2 other children, Logan and Anaya. On top of that, they also run a nonprofit organization.

While they understand the reason for Kael's behaviors, there are some days when they feel downright frustrated. When one of them notices the other seems tense, they have learned the importance of stepping in to help.



Even if it's a hard day for both of us, but one of us is a little more on edge, you have to take a deep breath and say, 'Okay, I'll step in today. I'll let you take a break.' Because this journey can feel like a roller coaster."

– Monica

Avram and Monica also know how important it is to continue to listen and communicate with each other. They don't hesitate to share their feelings openly. One reason for that is they feel very few other people can relate to what they are going through. While they have a great support system, their level of being able to understand each other is unmatched.

Making time for yourself

In addition to being open and honest with each other about what they're feeling, Avram and Monica also encourage each other to find time to be alone and focus on their own needs. It can be difficult to get away, but they both agree it's needed. Everyone deserves a break.

For example, if Avram notices that Monica needs some time for herself, he will grab the kids and go for a long drive. Sometimes he'll stop at the grocery store and pick up a few things, or he'll take them to the park. This approach works well for both Monica and Kael. Monica is able to get some alone time, and Kael can calm down or let his energy out.

Avram also likes to drive on his own when he wants some alone time. He'll listen to audiobooks, especially ones that are motivating and inspiring to him.



“It helps to hear stories from other people who are facing adversity and get different perspectives on everyday life. I like to daydream about how to shift, or change, to be a better person, father, or friend.”
– Avram

When Monica is able to take a break, she really enjoys meditation, and even considers it a lifesaver for times when she's feeling anxious. She uses the time after meditation to express how she's feeling to Avram or her children.



Monica also tries to get out and spend time connecting with her friends. Whether it's over dinner or just talking on the phone, it feels good to disconnect for a bit and enjoy a chance to socialize and feel supported.

Spending time together

Finding time alone to practice self-care is important, but Avram and Monica also try to find times when they can be alone *together*, without their children. They feel fortunate to have family nearby who can help take care of their children. So they try to plan a date night every week or so, where they drop their kids off at a grandparent's house. Their favorite date nights include going to dinner and seeing a movie, or going out and spending time with friends.



“Those type of moments help because we’re completely disconnecting and trying to have a good time. We talk about different things that have nothing to do with Hunter syndrome. That helps us get a little breather from our everyday life.”
– Avram

No matter what challenges the day holds, Avram and Monica face them together—a united front full of love.

Five ways Avram and Monica practice self-care

1

Try to set a planned time when you focus on yourself.

Whether it's for 10 minutes or an hour, work with your partner or loved ones to set aside time when it's all about you.

2

Step in for each other when times are tough.

If you see your partner or loved one frustrated or upset, ask what you can do to help. And when you feel that way, remember to communicate how you're feeling.

3

Allow yourself moments when you can step away.

Sometimes it can be helpful to create some space for yourself or your loved one. Avram likes to go for a drive to decompress. Other times, he'll grab the kids and go out to allow Monica some time to herself.

4

Focus on the things you love to do.

Think about the things that make you happy. For Avram and Monica, it's meditation, listening to audiobooks, and spending time with friends.

5

Reach out to support groups.

When you're feeling burnt out or are looking for advice, support groups can be a great resource. Someone else may be going through a similar situation and can help cheer you on.

