

FACE the FIVE

Signs for Rare Caregivers to Notice

Being a caregiver for someone with a rare disease presents unique challenges that significantly impact mental health. Over 70% of caregivers experience high levels of stress, with 65% reporting depression and 53% anxiety. Many caregivers feel guilty prioritizing their health, with 72% experiencing self-care guilt. Give an Hour's "Five Signs" provides a common language to understand how emotional struggle can show up for rare caregivers, along with ways to show support and respond. Recognizing these signs is crucial for family members and loved ones, as it enables them to provide timely support, reducing the risk of burnout and promoting a healthier caregiving environment.

Know the Signs and What they Look Like



PERSONALITY CHANGES

Your loved one may seem different exhibiting behaviors that don't align with their usual self.

Stressed-out, checked-out, frequently anxious or depressed, acts differently than 'normal', eerily "at peace" or joyful when previously stressed/depressed.



UNCHARACTERISTICALLY ANGRY, ANXIOUS, AGITATED, OR MOODY

Your loved one may struggle frequent mood swings.

Lashing out, angry outbursts, panic attacks, self-soothing. Always in 'crisis mode', feeling repeatedly triggered. May happen with or without a clear trigger.



WITHDRAWAL OR ISOLATION FROM OTHER PEOPLE

Your loved one might pull away from family and friends, signaling a need for support and understanding.

Not responding to texts, excessive malaise or sleeping, Needing to be alone. Not showing up for planned activities, housebound or signs of agoraphobia, avoidance when questioned.



MAY NEGLECT SELF-CARE AND ENGAGE IN RISKY BEHAVIOR

Financial strain, physical limitations, and emotional distress can contribute to neglecting self-care or engaging in risky behaviors.

Reckless or irresponsible spending, substance use, sedentary lifestyle/lack of physical activity, hair matting from poor self-care, change in appearance, "Depression House", significant weight gain or loss. Excessive sleeping.



OVERCOME WITH HOPELESSNESS AND OVERWHELMED BY CIRCUMSTANCES

Your loved one may experience extreme or prolonged grief, feelings of worthlessness, or guilt.

Verbal expressions of distress: "There's no point in going on", shutting down, masking feelings, making end-of-life plans, suicidal thoughts, self-harm, or worrisome verbal statements, "It's hopeless".

WHAT YOU CAN SAY:

"I've noticed that lately when we talk or hang out, you seem distant, you don't seem like your usual self. Can you tell me more about what's going on? I want to find ways to support you."

"I can't imagine how stressful that must be. It's sound like you're having a really tough time dealing with all of this. I want to understand what you're going through. Can you tell me more about how you're feeling?"

"I've noticed that you haven't been responding to my texts like you used to, and you've been spending more time by yourself. It's important to take the time you need for yourself, but you don't have to do this alone. You can lean on me for support, I'm here if you need someone to talk to."

"This might be difficult to talk about, but I've noticed you've been drinking more lately, and I'm really concerned about you. I just want to make sure everything is okay. I'm here for you. Do you feel comfortable opening up about that?"

"I understand it can be hard to open up and I want you to know I'm here for you. From a sincere place of concern I want you to know that I've noticed you've been really struggling lately. Are you having thoughts about hurting yourself?"