

# Breaking the Cycle: Addressing Substance Misuse in the Rare Disease Community



A chronic rare disease can significantly affect the mental well-being of both patients and caregivers, often leading to substance misuse. Patients may use substances to manage chronic pain and emotional distress, while caregivers might turn to alcohol or other substances to cope with stress and burnout. Addressing these issues requires a holistic approach that includes mental health support and effective coping strategies tailored to individuals in the Rare Community.

## Risk Factors for Substance Misuse in the Rare Community

-  **Chronic Pain and Discomfort**
-  **High stress or burnout due to the demands of treatment, frequent medical visits, and the burden of caregiving**
-  **Acute or perpetual emotional distress, such as frustration, sadness, or isolation related to the disease**
-  **Lack of social or emotional support**
-  **Financial strain from medical expenses or caregiving costs**
-  **Inadequate access to effective mental health care or pain management**
-  **Unaddressed mental wellness issues, including anxiety, depression, and feelings of hopelessness**



**Are you concerned about your substance use habits or those of a loved one?**

Take our **self-assessment** to reflect on your habits and understand their impact. This self-assessment is **not a diagnostic tool** but can help you identify areas of concern and encourage you to seek professional support if needed.

## Strategies to Prevent or Address Substance Misuse in the Rare Disease Community:

-  **AWARENESS** Education and Awareness of the impacting rare disease and addiction
-  **MEDICATION** Medication Management and Collaborative Mental Health Care, including specialty physicians and addiction interventionists.
-  **GROUP SUPPORT** Peer Support Groups and access to a Rare Care Community
-  **REDUCE STRESS** Stress reduction techniques and pain management programs
-  **FINDING JOY** Healthy outlets (enjoyable activities, spirituality, humor)
-  **CONNECTION & UNDERSTANDING** Open dialogue with family, support networks, medical specialists, and mental health professionals
-  **INTERVENTIONS** Substance Misuse Screening and Early Intervention



**If you are a rare patient or caregiver with a history of substance misuse, coordinate care between your primary and specialty physicians, mental health professionals, and addiction specialists.**



**Mental health struggles may lead to increased substance use**

**Substance use exacerbates mental health problems**



## Are you concerned about your substance use habits or those of a loved one?

Take our self-assessment to reflect on your habits and understand their impact. This self-assessment is not a diagnostic tool but can help you identify areas of concern and encourage you to seek professional support if needed.

### How often do you use substances?

- Daily
- Weekly
- Monthly
- Rarely

### Have you noticed any changes in your behavior or personality when using the substance?

- Yes
- No

### Has your substance use affected your daily responsibilities, such as work, school, or family obligations?

- Yes
- No

### Do you use the substance to cope with stress, anxiety, or other emotional problems?

- Yes
- No

### Has your substance use affected your relationships with friends, family, or colleagues?

- Yes
- No

### Have you experienced withdrawal symptoms when attempting to reduce or stop usage?

- Yes
- No

### Do you feel unable to function normally without using the substance?

- Yes
- No

### How much of the substance do you use each time?

- A small amount
- A moderate amount
- A large amount
- Varies

### Do you engage in risky or dangerous activities when using the substance?

- Yes
- No

### Do you find it difficult to complete tasks or maintain focus due to substance use?

- Yes
- No

### Have you experienced feelings of guilt or regret after using the substance?

- Yes
- No

### Have you tried to cut down or quit using the substance but found it difficult or impossible?

- Yes
- No

### Have you noticed that you need to use more of the substance to achieve the same effect?

- Yes
- No

### Has substance use led to financial problems, such as spending money needed for other essentials?

- Yes
- No

*If you find that you have answered "Yes" to multiple questions, it may be helpful to speak with a healthcare professional or seek support from a trusted individual or support group. Remember, seeking help is a sign of strength, not weakness.*