

Emotional Health and JM

Adolescents and young adults with Juvenile Myositis experience depression at rates two to three times higher than peers in the general population.* Researchers do not know yet whether mental health problems in JM are caused by the underlying illness (from inflammation), the treatments, genetics, or the challenge of living with a chronic and rare disease. What we do know is that patients, parents, clinicians, and researchers rank mental health as a critical research priority for Cure JM.

Cure JM Foundation recommends that mental health assessment and treatment be an integral component of comprehensive care for patients with JM, including those in remission. To this end, Cure JM is currently developing resources to help pediatric rheumatologists screen for mental health issues and recommend further evaluation or treatment if warranted. Additionally, a special committee of the Childhood Arthritis and Rheumatology Research Alliance (comprised of physicians, behavioral health specialists, patients and parents) is currently working on Consensus Statements for Assessment and Treatment of Mental Health to be published and shared with the broader rheumatology community.

The following information will help you better understand the signs and symptoms of depression and anxiety and how to find support.



Know the Signs of Depression⁺

Depression (major depressive disorder or clinical depression) is a common but serious mood disorder. It causes severe symptoms that affect how you feel, think, and handle daily activities, such as sleeping, eating, or working. You may be suffering from depression if you have been experiencing some of the following signs and symptoms most of the day, nearly every day, for at least two weeks.

- Constantly feeling sad, anxious, or even “empty,” like you feel nothing
- Feeling worthless, hopeless, or like everything is going wrong
- Spending more time alone and withdrawing from friends and family
- Not doing as well at school
- Losing interest or pleasure in activities and hobbies that you previously enjoyed
- Eating or sleeping more than usual or less than usual
- Feeling tired always (and not related to JM)
- Having trouble concentrating, remembering information, or making decisions
- Having aches or pains, headaches, or stomach problems (not related to JM)
- Thinking about dying or suicide or trying to harm yourself

Know the Signs of Anxiety⁺

Generalized anxiety disorder leads to excessive anxiety or worry most days, for at least 6 months, about a number of things such as personal health, work, social interactions, and everyday routine life circumstances. The fear and anxiety can cause significant problems in social interactions, school, and other areas of life.

Generalized anxiety disorder symptoms include:

- Feeling restless, wound-up, on-edge, or irritable
- Having sleep problems or being easily fatigued (and not related to JM)
- Having difficulty concentrating; mind going blank
- Having muscle tension
- Difficulty controlling feelings of worry

JM-Specific Factors Contributing to Depression and Anxiety

- Worrying about flares
- Feeling distressed about changes in appearance
- Living with a chronic and unpredictable disease
- Fighting pain, fatigue, weakness, and other disease symptoms
- Taking multiple medications with emotional and physical side effects
- Coping with hospitalizations, infusions, injections, procedures, and surgeries
- Transitioning from pediatric to adult care
- Feeling alone / isolated due to rarity of JM
- Lack of understanding from friends and relatives about JM



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Sources:

^{*} Knight, Andrea. Mental Health Needs of Juvenile Myositis Patients & Potential Interventions. 2018 Update on JM Care & Research. June 2018.

^{*} Prevalence of Depression in Adolescents. National Institute of Health. 2016. www.nimh.nih.gov/health/statistics/major-depression.shtml

⁺ National Institute of Mental Health

This material is for informational purposes only, and is not a substitute for medical advice, diagnosis or treatment provided by a qualified mental health or health care provider.

How to Get Help

Seek professional care:

- Find a mental health provider or treatment center at the *Psychology Today* website: www.psychologytoday.com/us/therapists. Providers can be sorted by zip code, insurance, issue, type of therapy desired, language spoken, etc. "Talk Therapy", medications, and a variety of other therapies are available to treat depression and anxiety
- Speak to a social worker or psychologist (if available) at your rheumatologist's or primary doctor's office, or at the hospital
- Consult a guidance counselor, psychologist, social worker or nurse at school

Find Support Systems:

- Family and friends
- Cure JM support groups / local support groups
- Cure JM regional chapters
- Cure JM conferences, walks, and events

Practice Self-Care:

- Mindfulness / meditation / yoga / massage
- Exercise & fun activities
- Good sleep habits
- Nutritious foods

Crisis Hotlines in the U.S.

Call 911 in the event of a mental health crisis (urgent threat of self-harm or harming others)

Suicide Lifeline: 800-273-TALK (8255)

The Suicide Lifeline provides 24/7, free & confidential support for people in emotional distress, as well as prevention and crisis resources for you or your loved ones.

Crisis Text Line: Text HOME to 741741

TXT 4 HELP: Text the word "safe" and your current location (address, city, state) to 4HELP (44357) which allows you to text live with a mental health professional: www.nationalsafespace.org/txt-4-help

National Help Line for Substance Abuse: (800) 262-2463

National Institute on Drug Abuse Hotline: (800) 662-4357

Eating Disorders Awareness and Prevention: (800) 931-2237

National Youth Crisis Hotline: (800) 442-HOPE (4673)