

## Self-Care and Coping Skills FAQ's

I am the Mental Health Coordinator for Cure JM. I am also a former counselor and mom to a JM young adult. Since her diagnosis, I have been managing stress, anxiety, and learning to care for myself for more than 15 years. I have also led coping skills workshops at our Cure JM annual conferences and writing workshops for caregivers nationally.

### *Why should a caregiver take care of themselves when their child has JM?*

When your child is first diagnosed with JM your thoughts and much of your first few months are spent learning about the disease and caring for them. But eventually, if you don't also listen to your own needs, you will burn out. You can become overly anxious, depressed, and perhaps not as able as you might be, to advocate for your child's needs. When we are flooded with emotions or anxiety we are not thinking as clearly as we might. If you have other children and a partner/spouse, you can feel depleted very quickly. Having a child with a chronic illness effects the whole family. Some things will have to change to adapt to a new "normal;" this includes putting your needs into the mix along with your JM child and other family members.

This is where having time, and maybe even regular plans for self-care, can be an effective anecdote to those experiences.

### *What can I do for myself as a caregiver?*

One of the first things I ask caregivers is to *assess their strengths and challenges*. Here is a check list, see what needs more attention or what needs to change.

- sleep
- diet
- exercise
- social connections—include family & friends
- work requirements—if you have a job outside the home or in addition to your family
- finances
- spiritual life—if you belong to a church, synagogue or mosque

### *What else is affecting your caregiving life?*

- Do you need to learn more about the disease?
- Do you have to spend a lot of time getting to and from doctor's appointments?
- Are the medicines your JM'er takes wreaking havoc with them and consequently you and other family members?
- Other?

### *What can I do for myself once I've assessed my needs?*

- What feels good to you? a hot bath at night? a walk or run or other exercise? Not cooking every night or making sure you have a home cooked meal once or more a week?
- Do you need someone else to spend time with your kid(s) and give you a break?
- Would connecting with other JM families help center you?
- Breathing exercises, mindfulness meditation, yoga?

- Creative outlets—writing, painting, music, dancing, other?
- Time for fun activities
- Do you need financial help? Who can help you figure this out?
- Advocacy—working to help others in the same or similar situation
- Would seeing a therapist help you, not just your child?
- Do you need anti-anxiety or antidepressant medications?
- What else do you know about yourself that helps you cope?