

# Living Well With Mast Cell Disease

Considerations for emotional support, self-care, and a  
fulfilling quality of Life

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# Congratulations! You've Been Diagnosed!

## Now What?

### Learning To Live With MCD

- Learning Body Signals
- Learning Triggers
- Educating Others
- Becoming Your Own Best Friend



# Being Your Own Best Friend

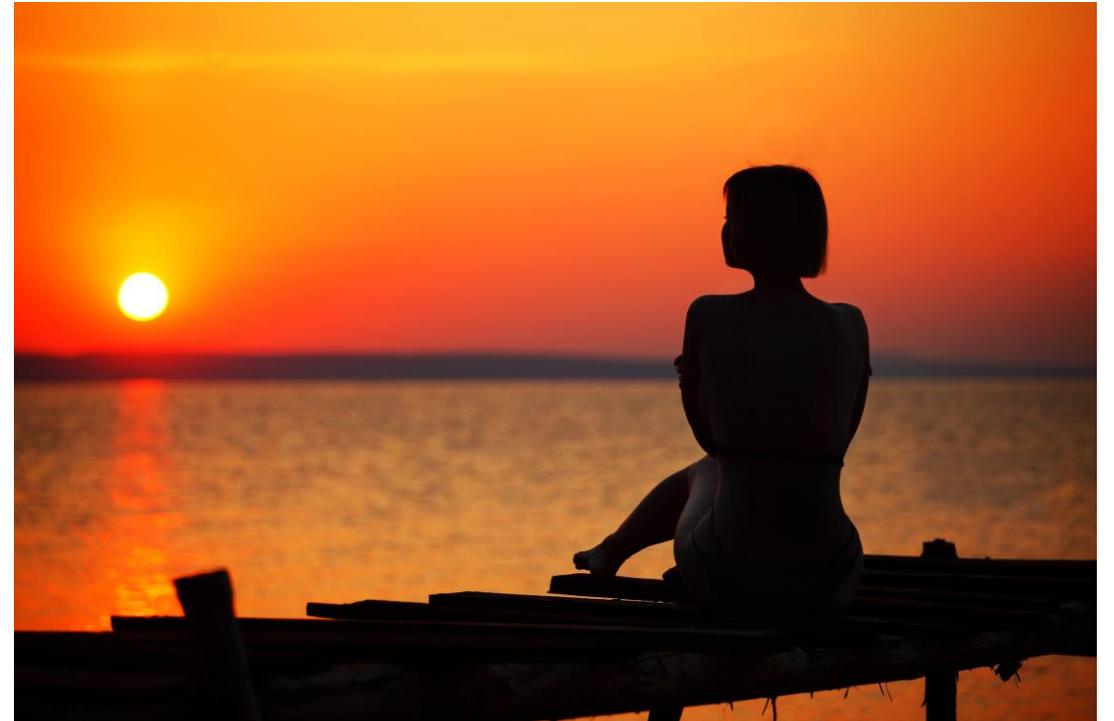
- Pause to consider what has happened
- Acknowledge the disease
- Reflect on the change in status
- Grieve losses
- Communicate
- Start a symptom journal
- Start a rage journal
- Start a daily journal
- Develop a gratitude ritual
- Engage in self-care



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# Emotional Well-Being

- Allow all emotions
- No such thing as a “wrong” emotion
- Tell yourself the truth, always
- Beware of limiting thinking
- Reaching for the good
- Reaching out & letting go



# Perspective



- Awareness of others
- Saying thank you
- A beautiful gaze
- 10 Reasons why I have it so good
- I'm lucky that...

# Cultural Myths

## Obstacles to healing

- If you are really sick, getting a diagnosis is easy
- There is a pill for everything
- One must conquer disease like a superhero, then create a charitable foundation... or something like that
- People who are really sick look sick
- “Rest” is a codeword for lazy
- If a “lifestyle change” fixes it, they aren’t really sick



# Dealing With Others



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- To explain, or not to explain?
- Using the fewest words
- Embracing the people who show up
- Stating your needs
- Creating Boundaries
- Games People Play
- Saying goodbye
- Saying hello
- Trusting the flow of life

# Trusting Yourself

- You are the expert in You
- Beware the Double Bind!
- Talking to yourself
- Talking to your body
- You, yourself, and the mirror (aka Identity is Plastic)



# 17 Reasons They Aren't Supporting You

## (And none of them are your fault)

- They are dealing with something big in their own life
- They don't know how to sit with suffering
- They aren't comfortable with sick people
- They don't know how to help you
- They are self-centered
- They don't know what to say
- They assume you want to be left alone
- They don't believe you
- They can't accept your changed circumstances
- They lack empathy
- They don't want to be inconvenienced
- They really, really love their artificial fragrances
- Vulnerability is scary to them
- They don't like change
- They are afraid of doing something wrong
- They aren't as compassionate as you are
- They don't value others

# Ideas for Self-Care

- Read a great book
- Read a trashy book
- Take an unscented bubble bath
- Meditate
- Listen to soothing music
- Dance— even if just moving a little in bed
- Buy yourself a little present
- Explore a new interest
- Look at something beautiful for a few minutes
- Write yourself an encouraging letter
- Get an unscented massage
- Dress up a little today
- Watch a favorite movie
- Find a place for 15 minutes of silence
- Say no
- Say yes
- Find a new hobby
- Make a gratitude list
- Deep breathing

# Tips for Engaging the Parasympathetic Nervous System

- Meditation
- Deep breathing
- Laughing
- Play soothing music
- Surround yourself with beauty
- Happy dances
- Spend time with good friends
- Write out a happy memory
- Gardening
- Yoga
- Make a list of ten good things that have happened today
- Think nice thoughts about someone you love
- Smell something comforting
- Napping

# Tips for MCD Thrivers

*There are no days off from MCD, but the days you have with MCD can be good*

- Turn off that busy mind for awhile
- Have a daily spiritual practice
- Make and keep a “safe zone” in your home—No triggers, no trespassers
- Eat a healthy diet
- Identify and eliminate triggers
- Take care of your emotional health
- Find a good listener that you can talk to
- Be a good friend—to yourself and others
- Organize your home and life around your disease
- Accept help!

# Tips for Finding Emotional Support

- Find a therapist who specializes in chronic illness
- Let go of the people who have proven they aren't there for you
- Embrace the people who show up for you
- Join support groups or on-line chats for people with MCD
- Read books on inspiring healing stories (self-support)
- Keep a positive attitude as much as possible.
- Quit support groups or on-line chats that are upsetting or too symptom focused for your current needs
- Say what you need
- Say thank you to people who do things for you
- Remember, your disease is not a punishment (self-support)
- Offer reciprocal support to others in your life

# Rethinking Self-Care

- Self-care is for the strong, even when they feel weak
- Self-care nourishes superpowers
- Self-care is a human necessity, not an indulgence
- Self-care helps the body get into “rest and repair” mode
- It’s OK to reschedule plans in order to take care of yourself when necessary
- Rest is an activity
- It’s ok to want to be alone sometimes
- It is normal to have a full range of emotions. Letting yourself feel what you feel is OK. Finding an appropriate way to express it is crucial
- When there are competing needs for resources, it is ok to use them on yourself sometimes

# A Rage Journal?

## *What?!?*

### **Yes, A Rage Journal.**

- A rage journal is a private, handwritten book where you honor and express your uncomfortable, or socially-frowned-upon feelings. It is a normal human response to a disease as miserable and disruptive as MCD can be to feel angry, frustrated, sad, and downright rageful at times. Further, sometimes the disease itself makes people feel irritable. It does no good to engage somebody in a fight when, really, it is the disease talking.
- Getting these feelings out in a safe way helps your psyche let go of them. Perhaps more importantly, writing them down often opens lines of thought that lead to solutions or helpful conclusions.
- Why handwritten? Computers files can be hacked, plus, the internet is forever.
- *Tip:* Hide this journal well.

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