

Caregiver Mental Health



Becoming the Person You Need to Be to Care for Severe and Very Severe ME

Inner strength is not a prerequisite for becoming a caregiver. We are thrust into this role in spite of everything, including our own flaws and weaknesses. No access to expensive therapy? This straightforward guide requires similar hard work, and just might do the trick if you're willing.

Grieve thoroughly, vanquish your past ghosts, and recognize past trauma that could be complicating your relationships. Learn to be present for your suffering person, and to find a new path to your own happiness in spite of the tremendous pressures and sacrifices that caregiving requires.

by Galen Warden

GRIEVE YOUR LOSSES

- You've lost so much to make their losses survivable.
- Fully experience your own grief.
- Don't minimize it. This is traumatic.
- Find the bottom of your grief, till you can go down no further.

You have devoted your time, effort, and finances to helping someone who's suffering, so they can hold on one more day.

You've done so much to make their losses survivable. But what about what you've lost?

Your person needs you to be a rock, but when you're alone, put down that role. Be your vulnerable self.

Grieving might help you get through that personal pain so that it doesn't haunt you: Experience grief as fully as possible.

Grieve whatever you've had to let go of to become a caregiver. Grieve whatever you were looking forward to that you may never have now.

Don't pretend it's not painful if it is.

The experience of acknowledging your losses – your level of grief - needs to match the tragedy of those losses.

Then, it's like you've just stuffed yourself with a Thanksgiving Dinner of grief, and you're satisfied. After you've really grieved, you'll be surprised that you might be able to relax and accept your new role with grace.

You can become that rock they need—not just for them, but for yourself—when you've made that important journey to the bottom of your grief.



Everything from medications to toothpaste is at the ready by Strazza's bedside.

"I've lost my identity. I've lost my freedom. I've lost my independence in almost every sense you can imagine."

James Strazza

This is my son, James, in USA Today when they did their first story about us in 2022.

Everyone with Severe ME/CFS feels unimaginable loss. But caregivers also feel their own losses.

What have you lost that hurts the most?

What are you the most angry about?

DROPPED INTO THE STORM

- You carry the most vulnerable cargo.
- No preparation. No escape. You will make mistakes. Be kind to yourself.
- No charts... you will draw your own map.
- Trust your wits, your power, your resolve.
- You must, therefore, you can.

You're navigating a ship through a storm with no charts, carrying the most vulnerable, suffering person in your ship. They're depending on you to figure this out, but you're out of your depth.

Do not feel guilty when you break down.

Nothing I am saying is meant to be a judgment or rebuke. *This is impossible stuff.*

You will be angry. You will say or do things you regret. You will make mistakes. It is OKAY.

Love is all the motivation you need to call on your wits, your power, your resolve.

When you've had a good cry over whatever is going wrong at the moment, take the time to hunt down resources online: reach out to people with experience. Make new friends.

Learn what you need right now to survive the current storm. Ask others about tools, resources.

It could be the most practical thing in the moment—like where to find one of those water bottles with a long straw—ask for help whenever you need it.



I grew up on sailboats so I often find my metaphors there. Do you feel lost at sea in a storm? I want to help you through it if I can.

What's the worst thing about your storm?

What do you feel guilty about?
"I forgive myself for..."

Can you prevent that in the future?

FINDING YOUR WAY

- What can this new life look like?
- Your narrower world is not empty.
- Find small treasures to celebrate.
- Help yourself as much as your person.

Once you grieve your old life and dreams, Once you've released that vision of your life, you will benefit from a new vision.

Instead of fighting it, dream up a new image of yourself thriving in your new reality.

What could your best life be in your new circumstances?

For example, you can't run out to restaurants like you used to. But, perhaps, while someone that you trust is with your person, you can treat yourself to a once-a-month lunch date with a friend, a game of mahjong, or a massage. Make it happen.

Consciously experience gratitude for every small pleasure. Your morning coffee, the smell of rain.

Yes, your world is much smaller. But it's not empty. Purposefully enjoy what can be enjoyed.

After you've grieved and released that former concept of your life, celebrate the little things that make you feel like you.

For me, it's no longer going to craft fairs, taking trips, or scavenging garage sales. And that's ok now, because I've grieved that loss.

I'm free to find what makes me happy now. And I do.



There's nothing like seeing the sun break through after a harsh storm. The hope, the relief, the achievement of having weathered extremes that could have drowned you but did not.

What are three things that you can still enjoy in your life?

What will you promise yourself you'll make time for?

Who can you enjoy a little break with once a month?

MY HEALTHCARE JOURNEY

When James was first completely dependent on me I was so overwhelmed.

I had a constant, surprising soundtrack running through my mind: "I want a divorce."

Well, I am divorced, and I'm not married to my son, so why was that the broken record?

This was making every moment harder and harder.

My son's anger about being sick and helpless reminded me of my ex-husband's anger.

I resented my son. I resented my circumstances.

I took it personally. I felt invaded. Vulnerable. Trapped. I was desperate to escape.

I knew this bitterness was not sustainable, so I sought therapy.

For me, therapy meant staring down the villains in my past and letting them know who was boss, from my neglectful mother to my mentally abusive husband.

I had to grieve how they had failed me. I had to allow the rage they deserved, that I had never let loose. So I let loose. I had days and days of crying when I wasn't with James. It was very hard work.

I dug deep. I examined hard. I found the nasty little barbs that were still embedded like fishhooks under my skin and I ripped them out.

I withdrew my permission for those people to hurt me. And it worked. The resentment toward my son stopped completely.

After a lifetime of shrinking from conflict and being a doormat, I became a fighter that could stand up, negotiate, and break down barriers on my son's behalf.

Eventually, my son began treating me with kindness. I never demanded it. I believe he saw that my love was genuine, in spite of his anger and criticisms.



This impossible situation gave me the gift of finding myself when I could have gone a lifetime holding myself back.

What is your self-talk like?

What toxic thoughts block your logical response to things?

Who are the ghosts that still have their barbs in you?

IDENTIFY YOUR TRIGGERS

- Examine your past for abusers, betrayers, and manipulators.
- Target those ghosts with your strongest venom and free yourself.
- Your sick person can't trigger you if you've banished these origins.

Work on your past traumas. Are you defensive because of self-doubt? Do past hurt feelings cause overreacting?

Look into your past for the source of your insecurities or anger. Judge those experiences again, now that you're more mature and experienced.

Re-examine how people treated you from your current point of view. They can't hurt you anymore. De-fang them. Declaw them. Give your past self that gift of revisiting injustices against you.

The person you care for is not trying to hurt you. They are trying to survive. They're furious, betrayed, abandoned by their friends.

Allow the sufferer their rage, their fear, their criticisms of you, as an outlet they need to survive this.

This is their reality right now—and you need to be present to allow them their experience without tangling it up with yours.

Be a mirror for them. Acknowledge their right to be enraged by all of this, especially if they're too sick or too weak to actually have a good cry.

Their criticism of your actions might be overblown, but that's ok. They are too wounded to take care of you right now.

Give them permission to be mad at you if that's what they need to do in their state of helplessness. They can't punch their pillow. You may be the only punching bag they've got. Let their criticisms be your gift to them. Be Teflon and let it just slide off you.

It will get better.



You don't deserve this difficult role. You deserve a happy life. But this difficult role just might be how you find that.

What is the most hurtful thing they have said to you?

Can you be Teflon and let that slide off for their sake?

Can you forgive them for not taking better care of your feelings?

YOUR BETTER SELF

- This life of sacrifice changes you.
- Your values and priorities shift.
- You will gain the rare joy to be satisfied with less and grateful for more.

Acknowledge, appreciate, celebrate the warrior you have become.

When you've gone through your own version of deeply grieving,

when you've made your mistakes and forgiven yourself,

when you've faced down your past ghosts and yanked their barbs out of you,

you will come to see that this life of caregiving is a gift you'd never in a million years have imagined you'd benefit from.

But you can benefit tremendously.

You are becoming the lion, the warrior, and the shelter from the storm that your vulnerable person needs... and the confident, peace-filled person you need.

You can't be petty, selfish, or inconsiderate anymore because you now value your peace above being right.

You will probably find that all of your values have shifted, and you are—and it's ok to acknowledge it—a much better person because of your sacrifices.



You are only refined like gold by the fires of difficulty if you choose to be.

Do you believe you can have inner strength and peace in spite of your circumstances?

Can you make your own mental health journey a top priority?

What is the one personal affirmation you need to tell yourself—and hear—every day?

My book, ***I Believe You: When Doctors Won't, a Mother Must***, comes out in 2025.

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