Advice for Caregivers from Caregivers

– Who are Sick Themselves

#MEAction's advocate, Denise Lopez-Majano, posed questions to caregivers, many of whom live with myalgic encephalomyelitis (ME) themselves, to collect their wisdom, advice and experience. Denise is a caregiver for her two adult sons with severe ME and has been facilitating #MEAction's caregiver calls for several years.

Join #MEAction's caregivers group here.

Caregiver: Bridget C. - person with ME and caregiver for parent(s)

What would you say to your early caregiver self to try to make the journey somewhat easier?

Give yourself grace. Try to talk to yourself as you would a friend. We give our friends really great advice and then somehow forget to tell ourselves the same thing. I'd also say: take time for yourself now. Caregiving is a long road that only gets longer. When people offer you time in the beginning, do not turn them down.

What would you say to other caregivers who also have a chronic disabling illness?

It's ok to put yourself first. Not everything is an emergency, even though most things feel like it. Figuring out the balance is a learning curve. You make the best possible choice in the moment, with the information you have. It is the best anyone can do.
It's frustrating, being chronically ill and a caregiver. You have a lot of the cheat codes gained the hard way, the long way. Your person may not want to hear it – or may not be able to hear it. This will cost you energy you have already spent on the issue. It's a chronically ill caregiver tax.

What would you want others to know about the complexities of caregiving in your situation?

In general, caregiving almost requires ESP sometimes. You're trying to predict your person and the

Universe in order to make things go as smoothly as possible. It's an impossible task, an improbable one. Mostly, it's an unseen one. And for those of us with invisible illnesses functioning as caregivers, we can become even less seen - and it is easy to slip into a place where you forget to make yourself seen.

It's daunting. Every choice you make while chronically ill - without factoring in caregiving - is a complex math equation where getting a decimal wrong (aka not pacing, trialing a new med, getting a virus, etc) means ending up in bed for months. Adding in being support for someone who has been there and supported you, it's differential equations with your life at risk.

How has what you learned as a caregiver helped you with your illness situation?

I feel so stumped here. I'm going to honestly say that systems I've had for decades with my chronic illness don't work now that it isn't just me; and now that my support team is no longer fully my support team alone. It feels like when we manage to reconfigure things to try to make systems work, the end post moves.
Illness isn't linear. It moves and shifts. Sometimes - maybe especially - when you think you have a handle on it.

Caregiver: Faith N

What would you say to your early caregiver self to try to make the journey somewhat easier?

Try to remember from the start that there are at least three journeys going on with each patient: (1) the journey the patient is on; (2) the journey that the caregiver is on; and (3) the journey that patient and caregiver are on together.

Each of you will end up in places where the other cannot go. Together you go places neither of you could go alone.

This is a way of saying: each person brings strengths and challenges to this journey. Sometimes the caregiver is the only one who can reflect the patient's strength back to them; sometimes this works the other way.

What would you say to other caregivers who also have a chronic, disabling illness?

Everyone has limits on what they can and/or should give to another person. Remind yourself constantly that the limitations of your own body do not reflect deficiencies of heart or determination.

Additional thoughts?

When we think of being a caregiver as providing services to those who cannot do, we get exhausted. When we remember that being a caregiver is the loving act of helping another person live life authentically, we get inspired.

Caregiver: Sue J

What would you say to your early caregiver self to try to make the journey somewhat easier?

Just take one day at a time. Drop as many other responsibilities as you can.
The boys are going to turn out fine! Better than fine - all their struggles turned them into caring, compassionate adults.

What would you say to other caregivers who also have a chronic, disabling illness?

It's almost impossible, but remember to take care of yourself, too. You won't be any use to the person(s) you're taking care of if you crash or worsen.

I didn't do this! As a mother, I always put my sons' needs first. If my son needed to be driven back and forth to school 3 times in one day so he could nap between required classes, then I did that, no matter how I felt. So … TRY to listen to your body and understand your limits.

Ask for help!! And be specific. My husband did a lot, but I know my friends would have helped more if I had asked. Most people who care for you want to help but don't know what you need.

What would you want others to know about the complexities of caregiving in your situation?

It's extremely challenging to care for others (not just our chronically ill sons but also my father-in-law who had dementia) when you are sick and limited yourself.

How has what you learned as a caregiver helped you with your illness situation?

I try to remember the things that I told my sons while they were growing up and sick, like just focus on the present and don't worry about the future. And find small joys in every day. And above all, listen to your body and let others know your limits—learn to advocate for yourself.

I even wrote a book with all of that advice in it, but I've found it harder to take my own advice! Sometimes I will hear a line from my own book, in a post or video, and realize I haven't been doing that for myself. It's a constant learning process. Even after almost 24 years of living with a limiting illness, I still need reminders.
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Additional thoughts?

Be kind and gentle with yourself - give yourself the same compassion you give to those you care for.

Caregiver: Laurie W. - Sibling caregiver

What would you say to your early caregiver self to try to make the journey somewhat easier?

The ME/CFS community is incredibly supportive, empathetic and knowledgeable. Many times, it may seem there aren't answers as you continually care for your loved one. In these times the community can provide guidance and resources to help carry you. Join online groups, connect and make friends with other people with ME/CFS and caregivers. They will help carry you through some of the hardest and darkest times.

The pacing concept can help caregivers too. Caring for someone with ME/CFS is an unexpected, lifelong commitment. Your loved one is suffering with a terrible disease and that deeply affects your life. As you would suggest to your loved one, don't push yourself too hard and listen to what you need. Consider how much you can take on in life and things you can let go of. Letting go can be very hard but you are living a different life now and that requires a different version of you. If you try to do it all, you may burn out.

Things can feel chaotic and overwhelming as an early caregiver. You are suddenly doing a complex job with no training or experience. As you lean into this new role, you will create new systems and processes to manage everything. It takes time but you will adapt life to surround and support your loved one. Seek advice online and from other caregivers. Many times people have already figured out what you are trying to solve.

Becoming a caregiver may include letting go of the life you envisioned. It can feel lonely and very isolating. You may feel like nobody understands how difficult life is for your loved one and for you. Find things to do that bring you peace when you can (e.g. meditating, writing, painting, photography, reading, listening to music etc.) Doing this can bring stillness to quiet the ever beckoning rumination of thoughts. You need peace and stillness to balance how deeply you must give all the time with loving presence.

Learn from the wisdom of people living with ME/CFS. Listen to your people with ME (PWME) and others in the community. This will help you take the best care of your loved one possible. Not only can PWME guide how they need to be cared for, they are incredibly wise about life overall. People living with ME/CFS can have very evolved souls and perspectives because they have figured out how to live through such suffering and hardship. Our world needs their wisdom.

Take things one at a time. Caregiving for severe ME/CFS can be overwhelming and exhausting. You don’t have to fix everything and many times you can’t. But you can do your very best to help your loved one and meet their needs. As things evolve you will learn with them and adapt.

Don’t expect too much so you can be surprised and thankful when good things happen. Don’t expect to “fix” your loved one, but help them in all ways possible. Don’t expect doctors to understand, many aren’t experienced with ME/CFS. Don’t expect to be a superhero, just do your best between everything caregiving and life demands. Don’t expect life won’t change, it always changes and the changes with ME/CFS can feel like a massive life transition.

Give yourself permission to ask for help from others. Don’t feel you have to do everything yourself. If people offer to help, open up and find ways to let them. If they don’t and you need it, find the courage to be vulnerable and ask. If you encounter wise resources in the caregiving community, lean on their knowledge, experience and kindness.

If you feel like you’re grieving, you probably are. Your loved one finally received an answer to their health issues and has been diagnosed. This is the beginning of the journey, not the end. As their illness progresses in severity, love them deeply through the many heartbreaks and losses. You may also experience many losses. These can bring grief, albeit ambiguous or disenfranchised, so be very tender with your loved one and yourself. Let yourself experience the emotions of grief, they are very natural. Grief is a part of life, as illness is a part of life.

You may feel like you are trying to be a medical professional without any training. This can be uncomfortable, unnerving and even scary. You will figure it out as you go and as needs present. Know that other ME/CFS caregivers around the globe have walked the same road and you are not alone. You will grow in caregiving as you have with other things you’ve learned in life. Someday you will be surprised how much you have learned and changed.

Caregiver: Anonymous

What would you tell your pre-caregiver self?

This is more difficult and more involved than you expect but there will be positives.

Don’t overdo it. Make sure you always have time to care for yourself. Too often – especially early on, we are driven/laser focused on finding the solution without understanding that this is a long-term journey. (It can be life-long)

Each day/hour is different.

You don’t know what you don’t know so ease up on the guilty feelings. Do what you can with what you have at the moment.

As caregivers age (and for those younger ones with impairments), they too often become more impaired and less able to do the caregiving they did before. So they have to do even more balancing of what gets done and what doesn’t. And the sort of care they provide. Sometimes they have to trade off with the person(s) they are caring for and have them do more caregiving when the primary caregiver is less able. It’s hard because one can’t plan for who is well and when they are, let alone if both/all are unwell simultaneously.

Knowing when to step back rather than stepping in. Knowing when to let mistakes happen rather than rushing in to prevent them or to fix them. When to listen without planning your response.

Caregiver: Anonymous

What would you want others to know about the complexities of caregiving in your situation?

No matter how awful it has seemed from the outside, it can actually be worse than people imagine at times. Having ME/CFS is very traumatic and being a caregiver for someone severely ill with ME/CFS is also very traumatic. I have witnessed a level of ongoing, profound suffering most people can’t fathom, and feel powerless to rescue my loved one despite trying all the time for many years. I am forever changed.

How has what you learned as a caregiver helped you with your illness situation?

I learned to listen to my body and rest if I need to. There may not be simple answers and fixes to help me feel better. You must advocate for your own health. It can be harder to advocate for yourself than your loved one.