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MECFS



What your loved one
needs you to do.

PART 2



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In a follow on to "MECFS: What your loved one needs you to know" this post addresses the practical considerations. What does your loved on need you to do? And perhaps equally important, what do they need you not to do.

In addition to a basic list of do's and don't I will also include some more nuanced situation guides.

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DO

- Support your loved one financially, physically, emotionally and in whatever way you can to reduce the physical burden on their body
- Tell your loved one that their value is not tied to their productivity
- Encourage them to rest and reduce stress
- Encourage them to use mobility aids like wheelchairs, walkers, commodes, shower chairs and bath lifts
- Tell your friends and family about MECFS using resources from advocacy groups like ME Action.
- Support research into treatments for ME through foundations like The Open Medicine Foundation
- Read the NICE 2021 and Mayo Clinic 2020 guidelines to learn about what ME is and how it is treated

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DONT:

- Tell your loved one to "get better soon"
- Encourage your loved one to go back to work or school. (They already want to)
- Tell your loved one how "worth it" a crash is for attending an event with you
- Push your loved one to seek more medical care than they want to (There is not much doctors can do and too many appointment can cause PEM)
- Support treatments proven to harm ME patients like GET, CBT, Lighting Process, or any treatment based on the idea that ME patients are "deconditioned"
- Pay money to anyone who promises something too good to be true such as a supplement, device, or therapy that can rapidly cure ME. (If it sounds too good to be true, it is)

Situation: Extended Family

Often times extended family is somewhat left out from an ME patients journey. It can be extremely taxing for someone with ME to communicate with extended family regularly and we often have to miss most family functions. Here are some of the best ways to support your loved one if you aren't their immediate support network:

- Document and share photos and videos of the events we miss. We love to see you!
- Raise awareness for ME through protests, petitions, and sharing our stories. Our immediate family is busy caring for us so extended family is actually much better equipped to help raise awareness.
- Support our immediate family emotionally. Offer them a place to vent and give them spaces to be cared for rather than being the caregiver.
- Show that you support us with your actions. Take covid precautions seriously. Support disability pensions and the social safety net that keeps us alive. It might not feel personal to you, but it does to us.

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Situation: Medical Coordinator

With the explosion of new research funding for MECFS following long covid as a new variant of post viral illness (indeed many cases of long covid are disgnosable as MECFS) there are now many new drugs and treatments being tested in ME. Here are some things to keep in mind if you are helping your loved on get medical care.

- **Read read read research!** Cort Johnsons blog Health Rising is often a good place to start as he sumarizes evidence in an accessible format.
- **Be aware of dangerous treatments like GET and CBT.** Always look for patients who have been harmed by a treatment in addition to those who have benefitted to ensure you do not encourage your loved one to undergo a harmful treatment or procedure.
- **Remember that your loved one wants a cure desperately and can be easily convinced to try things.** In addition to helping them find treatment, make sure you also help them find acceptance of their illness through pacing and symptom management.
- **Make sure you do not propegate the mindset that your loved one needs to be fixed to be valuable.** Helping them find a treatment is great. But make sure they also know that you don't need them to get better to want them around.
- **Make sure they feel comfortable stopping at any time.** This is important to prevent patients from undegoing harm from treatments.
- **Leave room for rest.** Too many treatments can cause overexertion from appointments and medical interventions which can cause deterioration even if the treatments themselves are neutral or even good. Take your time and go one by one.

Situation: Spouse

Obviously no one wants to think that they would leave their partner because they got sick. If you are married you explicitly promised not to. But I have seen far too many marriages killed by this disease. So here's how to avoid the worst of it.

- Take care of your own mental and physical health. Make this your top priority. Your own health is your most vital resource.
- Get help. Do not try to be solely responsible for caregiving. Make sure you find other friends or family members who can provide care to give you breaks or seek to hire professional help. In particular, if your loved one needs 24/7 care you CANNOT be the only source. You will burn out.
- Have an exit plan. Yes marriage means in sickness and in health. Yes you should try to honor that. But you should also have a plan in place of how your spouse would survive without you. Where would they live? How would they survive financially? Who would support them? Having this plan means that neither of you is obligated to stay in the relationship should it become abusive (which in turn means you are way less likely to end up in an abusive situation).

Situation: Living With Parents

Many unmarried adults with ME move back in with their parents. Especially between the ages of 18 and 30. This scenario comes with its own challenges. Some things to think about and discuss include:

- **Seeing each other as adults.** Parents and kids have a unique relationship. Learning to see each other as full humans with flaws and strengths takes time. When the adult child is again living as a dependent of their parent this insight can be difficult and important to maintain and should be explicitly discussed.
- **Medical autonomy.** The adult child has medical autonomy but this may be unintuitive and its important for parents to try to remember to respect this autonomy.
- **Romance and social life.** The adult child may wish to date. This can feel awkward but should be discussed so that living at home doesn't stop the person with ME from finding a potential new support network.
- **Aging and sustainability.** Parents of a 20 or 30 year old child are likely getting to be getting old. It is not sustainable for them to work indefinitely, much less work and caregive. Conversations must be had about the long term future of both the parents and child so as not to lead to a deteriorating living situation with no exit.

Situation: Neighbors

Neighbors have the ability to be some of the most helpful allies to patients with MECFS. If your neighbor has ME, there are often so many small tasks you can do that make a drastic change to their quality of life. Some small things you can offer to do that can be incredibly helpful include:

- Taking garbage bins in and out for them
- Holding onto mail during times they are unable to get to the front door or mailbox or bringing in the mail for them
- Bringing food during crashes where they are unable to cook or get out of bed
- Avoiding loud noises in the morning or during times you know they are sleeping
- Providing wellness checks where you make sure they have access to food, water, and hygiene and calling a friend or family member if they need help

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Situation: Mental Health Crisis

People with ME suffer disproportionate rates of anxiety, depression and PTSD. This is understandable given the severe hardships of living with the disease. However, dealing with mental health crises in ME patients can be challenging because psychiatry has a long history of abusing ME patients and severe ME patients have died from being sent to psychiatric hospitals.

You should never send a police or ambulance "wellness check" to someone with ME. Especially someone with severe ME. These professionals are not trained to deal with people with ME and have potential to do severe harm.

If you are the loved one of someone with ME and know that they are in danger due to mental health crisis, you should either attempt to check on them yourself or send a neighbor or friend who understands their condition. If this is not possible, you should keep them on the phone or in contact with you until you can arrange for them to get help or until they are able to sleep.

This advice is primarily targeted at people with ME who have mental health effects due to their disease. For patients with severe mental health conditions commorbid to ME, the tradeoffs may be different. However, in all circumstances the harm of stress, physical exertion of travel, and medical gaslighting should be considered when making the choice of how to respond to a mental health crisis.