

# Supporting her through an energy-limiting condition

A 2-page guide for family, friends, and caregivers. She lives with a condition such as ME/CFS, long COVID, POTS, or fibromyalgia: her energy is very limited and runs out fast. Here is what that means day to day, and what to do.

**Her illness is real, even when it doesn't show and her tests come back normal. Your fatigue as a caregiver is real too.** The key is balance. Don't push her past her limits, listen for what she needs, and don't decide for her. At the same time, talk with her openly about how you're doing, and take care of yourself, because you both need a pace you can keep.

## 1. She crashes after effort

### WHAT'S HAPPENING

Physical, mental, or emotional effort can trigger a crash (post-exertional malaise, PEM). Symptoms get worse 12 to 48 hours later and can last days or weeks. Everyone has her own triggers, from walking and exercise to noise, stress, or too much socializing. Rest doesn't bring her back quickly.

### WHAT TO DO

- **Pacing** means staying inside her energy limits: spread effort across the day, rest before she's tired, and stop before a crash.
- **Track and look for patterns together.** Log crashes, sleep, activity, and heart rate variability (HRV), and look at what tends to happen 1 to 2 days before a crash. The same data helps her doctor take better care of her. The Welltory app makes this easy.
- **Agree on a quick energy signal**, like a number from 0 to 10 or green, amber, or red, so she can tell you how she is without having to explain.
- **Make a crash plan while she's well.** Decide who handles meals, kids, and errands.
- **During a crash**, keep things dim, quiet, and simple. Bring water and easy food, hold off visitors, and don't try to get her moving.
- **On good days, don't catch up on everything.** Help her save some energy for tomorrow.

## 2. Her energy budget is small

### WHAT'S HAPPENING

Everything draws on the same small daily budget, including lunch, a phone call, and a shower.

### WHAT TO DO

- **Plan around her limits and yours.** Look 2 to 3 days ahead, build in rest before and after events, and keep a Plan B.
- **Let plans change.** Canceling protects her energy. Don't take it personally or keep score.
- **Take on the costly tasks she's ready to hand over**, including parts of parenting and housework, and the invisible work of planning.
- **Skip "you just need to move more".** In 2021, the UK's NICE guideline stopped recommending exercise programs with a fixed, gradual increase in activity for ME/CFS. With PEM, pushing past her limits risks triggering crashes and lowering her baseline. Any activity should follow her limits and her care team.
- **Keep closeness in low-energy forms:** a film watched lying down, touch with no expectations. Sex draws on the same budget, so talk about it openly.

## 3. Standing up is hard

### WHAT'S HAPPENING

With POTS, less blood reaches her brain when she's upright. A line at the store or time at the stove can bring a racing heart, dizziness, or nausea.

### WHAT TO DO

- **Whatever can be done sitting or lying down, do it that way:** a chair at the counter, a shower stool, seated plans.
- **Use mobility aids without hesitation.** A wheelchair on long trips or days out saves her precious energy for the parts that matter to her.

## 5. Her immune system is fragile

### WHAT'S HAPPENING

For her, an ordinary cold can mean a long setback.

### WHAT TO DO

- **Take infections seriously.** If you're sick, keep your distance or wear a mask, and respect the precautions she asks for.



#### 4. Brain fog, pain, and sensitivity

##### WHAT'S HAPPENING

Less blood flow to the brain and an overloaded nervous system mean words go missing, decisions take effort, and light, noise, touch, and pain feel much louder.

##### WHAT TO DO

- **Help with decisions and leave her in control.** "Want me to pick what to cook, and you just say yes or no?" Offer specific help: "I'm at the store, what can I get you?"
- **Ask 1 question at a time,** and give her time to find words.
- **Share the mental load by agreement:** notes, shared lists, reminders.
- **Lower sensory load:** dim lights, close the curtains, bring sunglasses and earplugs to shops, and pick calm or familiar films without fast cuts.



#### 6. Her illness is invisible

##### WHAT'S HAPPENING

She can look fine, so many people, doctors included, doubt her. Doubt hurts most when it comes from the people closest to her.

##### WHAT TO DO

- **Believe what she tells you** about her body today.
- **Ask, then listen.**
- **Leave her choices to her:** what to eat and drink, how to sleep, which treatments to try.
- **Keep her in every conversation about her health,** and discuss your ideas with her directly.



#### How to talk with her

**Empathy** means feeling with her: notice what she feels and let her see it. "I can see how hard this is for you."

**Validation** means telling her that what she feels makes sense. You don't have to agree with everything or promise it will be fine.

##### A SIMPLE STRUCTURE

###### 1. LISTEN

without interrupting

###### 2. NAME

the feeling, as a guess

###### 3. VALIDATE

say it makes sense

###### 4. ASK

what would help

"I hear that... It sounds like you feel... That makes sense, because... What would help right now?"

- **Write messages she doesn't have to answer:** "Thinking of you, no need to reply."
- **Talk about feelings, yours too,** at a calm hour and never in the middle of a crash.
- **Keep sharing your life,** and ask about hers beyond the illness.

##### AVOID

##### TRY INSTEAD

###### DOUBT

"You don't look sick." "You're exaggerating." "It's all stress or anxiety."

"I believe you. Tell me what it feels like."

###### UNSOLICITED ADVICE

"You just need to walk more, sleep more, eat more meat."

"What has helped you before? Want me to look into anything?"

###### BLAME

"You brought this on yourself."

"What can I do to help?"

###### TOXIC POSITIVITY

"Stay positive, others have it worse."

"This is really hard. I'm here."

###### PRESSURE

"You keep canceling plans."

"Let's change the plan. We'll try again when you're up to it."



#### Take care of yourself too

Caring for someone through a long illness wears anyone down. Many caregivers feel compassion fatigue: the strain of caring for someone who suffers, again and again, with no clear end. Feeling tired, sad, frustrated, or guilty is a normal cost of empathy, and it doesn't make you a bad partner, parent, friend, or caregiver.

- **Don't be her only support.** Share the load with family, friends, or paid help.
- **Get support of your own:** a caregivers' group, a friend who listens, or a therapist. Acceptance and commitment therapy (ACT) has good evidence for easing caregiver distress.
- **Watch your own signals:** resentment, irritability, poor sleep. They mean your reserves are low.
- **Rest before you burn out,** and plan time for yourself.
- **Be honest about what you can sustain.** A calm talk now beats months of quiet effort.

This material was prepared for members of the **Welltory Energy Lab**, a community for women aged 35 to 65 living with energy-limiting conditions. The community can help her find support from peers with the same symptoms and discover her own pacing strategies. Join:

[app.welltory.com/community/welltory-energy-lab](https://app.welltory.com/community/welltory-energy-lab)