

HOW TO BE A DEMANDING DIPLOMAT AS A SEVERE ME/CFS CAREGIVER



GALEN WARDEN
A DEDICATED CAREGIVER AND MOTHER
OF AN ADULT SON WITH SEVERE ME/CFS

Caring for an individual with severe or very severe ME/CFS requires special knowledge and communication skills to manage medical care and the associated logistics. Galen Warden shares insightful and practical recommendations in her presentation, “How to Be a Demanding Diplomat as a Severe ME/CFS Caregiver.” This guide is a summary of her informative presentation. We recommend watching the [video presentation](#) or [reading the transcript](#).

LOGISTICS

Every aspect of practical care can make a significant difference. It is imperative to be vocal and specific about needs while maintaining a kind and factual approach.

Establishing Medical Proxy

Setting up healthcare power of attorney (medical proxy) is fundamental for streamlining the care process:

Key Points:

- **Permission:** Allows the caregiver to make medical appointments and access medical data like lab results.
- **Availability:** Available through each U.S. state and can be printed online.
- **Signatures:** Requires signatures from the person with ME/CFS, the caregiver, and a witness; no attorney required and excludes financial matters.
- **Process:** Once signed, provide a copy to the medical clinic and hospital for inclusion in the patient’s file. Inform new medical facilities or services of your authority, and they will guide you on providing the form.

More Information: Watch Galen’s video starting at minute 5:39.

GOVT. DISABILITY PROGRAMS

There are two types of government disability entitlement programs in the U.S.:

SSDI (Social Security Disability Insurance)

- Eligibility: Based on work history in the U.S.
- Benefits: Includes Medicare insurance.
- Application: Attorneys may assist in exchange for a percentage of backpay if granted.
- Backpay: Lump sum compensation for the period between application submission and approval.

SSI (Supplemental Security Income)

- Eligibility: For those who haven't worked enough for SSDI.
- Benefits: Includes Medicaid insurance.
- Application: Usually does not involve attorneys as there is no backpay incentive.

Application Process: Most are denied on their first application and must appeal.

Watch Galen's video from minute 8:56 for detailed information and check-out BHC's [disability resources](#).

TRANSPORTATION

Non-urgent gurney or wheelchair transportation services help reduce the risk of symptom exacerbation during necessary medical appointments.

Key Points:

- Resources: Medicare covers limited trips; Medicaid covers unlimited trips if deemed medically necessary by a doctor.
- Private Companies: Available but can be costly.
- Preparation: Notify transportation staff about specific needs, such as head support.

More Information: Watch Galen's advice at minute 19:25 and see her [Gurney Guide](#).

ACCOMMODATIONS

Appropriate accommodations can significantly reduce symptom exacerbation during medical appointments.

Key Points:

- Preparation: Communicate special accommodation needs due to a severe neuro-immune condition to medical office staff before appointments.
- Legal Backing: The Americans with Disabilities Act supports such accommodations.
- Example Requests: Quiet and dark waiting areas; instructions for protecting the patient from stimuli if separated during an appointment.

More Information: See examples at minute 27:46.

EDUCATING DOCTORS

When your doctor isn't familiar with ME/CFS, it's important to provide credible information:

Key Points:

- Diagnostic Code: G93.32
- Useful sites include:
 - CDC ([cdc.gov/me-cfs](https://www.cdc.gov/me-cfs))
 - Mayo Clinic's "[ME/CFS: Essentials of Diagnosis and Management](#)"
 - [U.S. ME/CFS Clinician Coalition](#)
 - [Batemanhornecenter.org](https://www.batemanhornecenter.org).

More Information: Watch the explanation at minute 33:36.

CAREGIVER SUPPORT

Caregiving for someone with severe ME/CFS requires support to prevent burnout and emotional overwhelm.

Key Points:

- Services: [Medicare](#) and Medicaid (by state) offer home health services through paid individuals.
- Profile: Create a detailed profile for prospective caregivers including expected tasks.
- Resources: Use platforms like [care.com](https://www.care.com) to find private caregivers.
- Training: Develop training materials and a tracking system for caregivers.
- Tips: Avoid allowing caregivers to manage medications.

More Information: Read Galen's blog post, "[You Need a Caregiver](#)," and watch this section of the video at minute 39:13.

COMMUNICATION STYLE

Effective communication is crucial for advocating for the person with ME/CFS:

Key Points:

- Approach: Be specific, kind, factual, and maintain authority without apologizing.
- Focus: Explain the condition (severe neuro-immune condition) and necessary accommodations without excessive detail.
- Request: Calmly and clearly explain medical needs and accommodations.



@severemecfs



@galenwarden

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