

Lunch & Learn Recap: How to be a Demanding Diplomat: Fighting for the Best Available Care in an Unaware System

January 18, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is still recruiting for two Long Covid studies. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.
- Lunch & Learn series is open for presenters in 2024. Email outreach@batemanhornecenter.org if you are interested in presenting to the BHC community.
- Send your medical provider(s) email address to outreach@batemanhornecenter.org and we will invite them to our medical education offerings.

The following information was shared by a volunteer presenter and attendees and does not necessarily reflect BHC guidance nor endorsement.

“How to be a Demanding Diplomat: Fighting for the Best Available Care in an Unaware System” by Galen Warden

Galen Warden is the mother of six children, including a 35-year-old son who is bed bound with severe ME/CFS. Her presentation is given from the perspective of a caregiver. She says:

- Be a demanding diplomat! Logistics can be a matter of life and death. As a result of that, you're going to have to communicate your needs patiently and kindly to individuals you come in contact with such as transportation professionals and receptionists etc. Unless it is a primary care provider, you do not need to educate them on the details of ME/CFS.
- For example, Galen goes into medical offices ahead of her son and explains to the non-medical staff that her son has a severe neurological condition and then proceeds to calmly ask for accommodations such as turning off the office music, and asking for a quiet room where he can wait for his appointment because he can't be exposed to

unnecessary talking and noise. It's not helpful to be upset or panicky about the situation.

- Healthcare Power of Attorney (POA) is extremely helpful and will open many doors for you as a caregiver. POA allows you to have conversations with doctors, make appointments, access clinical records, and help make medical decisions. A lawyer isn't needed. Utah's Health Care POA form can be found at:
 - https://www.galenwarden.com/_files/ugd/f31a2c_6c1b8e1713e04847a9f653812607a97d.pdf
- Government Disability Programs. Social Security Disability Insurance (SSDI) requires that the ill person worked a certain amount paying into the system and includes Medicare coverage. Supplemental Security Income (SSI) doesn't require years of working to pay into the system and it includes Medicaid coverage. With either program, the ill person can appoint a family member or anyone to represent them if they don't want to use an attorney during the application process. Educating the nurse practitioner and ME/CFS who evaluated her son for SSDI helped him to obtain the disability ruling. A lawyer may be helpful in getting SSDI in place, but they can be costly.
 - Good clinical notes from a provider that is educated or willing to be educated on ME/CFS are essential to getting approval for disability benefits. Educate your providers if you can!
 - Apply for disability benefits at <https://www.ssa.gov/disability>
- Transportation and mobility aids can be a game changer for office visits, testing, and procedures. Non-emergent medical transportation by gurney or with a wheelchair is available. Medicare and Medicaid pay for this service. Avoid the crash that can be triggered by having to walk long hallways, transfer multiple times, etc. and acquire a wheelchair or other mobility aid to suit your needs for your out-of-home visits and activities. They can be rented. Minimizing movement effort will help avoid crashing.
 - Be sure to kindly give them clear instructions about the specific needs such as protecting the head if the ill person can't lift their own head, or to remain silent because the ill person can't tolerate sounds.
 - Read Galen's blog post about transportation by gurney at <https://www.galenwarden.com/post/gurney-guide>
- Be firm and ask for accommodations in offices and other spaces as appropriate. Usually asking kindly and firmly is enough. Explanation is not always necessary, and phrases

such as “neurological condition” are often enough to get needed sensory accommodations and help for your patient or loved one.

- Don’t wait to get assistance from an additional caregiver! It’s important for family/friend caregivers to avoid burnout and get on board with a case manager because they can help guide you through the process of retaining a professional caregiver. Medicare and Medicaid pay for caregivers:
<https://www.medicare.gov/coverage/home-health-services>
- A descriptive profile on <https://www.care.com/> and for other agencies will make it easier to find the correct fit. Be very clear about sensory and movement needs, and that the position is not for a babysitter. Be clear about the desired demeanor and necessary tasks.
- Be the mother/father/spouse/caregiver that your person needs! Being hysterical, yelling, and letting people know how rough it is and how much suffering there is will work against you and be a distraction. Determine what your goal is in a given appointment or interaction and don’t say anything that doesn’t contribute to the goal. Be calm, direct, diplomatic, and strategic in your interactions with clinic staff, providers, and other helpers you encounter. You will win empathy with efficient and kind communication.
- Helpful links from Galen Warden
 - Website: <https://www.galenwarden.com/> or [severemecfs.com](https://www.severemecfs.com)
 - Posts
 - <https://www.galenwarden.com/post/gurney-guide>
 - <https://www.galenwarden.com/post/you-need-a-caregiver>
 - Tiktok: <https://www.tiktok.com/@galenwarden>
 - Instagram: <https://www.instagram.com/severemecfs>

Discussion Segment

- How do you talk to providers about ME/CFS when they are uneducated about the condition?
 - Provide them with scientific papers in the form of links or hard copies from reputable sources like the CDC and NIH. Galen and BHC have resources for this on their respective websites. Here is a resource BHC frequently uses: *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management* (Mayo Clinic, 2021)

- [https://www.mayoclinicproceedings.org/article/S0025-6196\(21\)00513-9/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext)
- Social Security Disability
 - Is a medical assessment necessary for disability approval?
 - Yes. Your own provider completes a medical evaluation form and the government agency will also assign a third-party medical professional to perform an assessment. The process can vary by state. Galen's TikTok channel has a video called The Clinical Disability Form.
 - Participant shared: A way to demonstrate lack of capacity to a disability judge is by recording a daily log of symptoms. I have migraines from ME/CFS and went onto American Migraine Association website and printed a log sheet that they provide. I kept that log along with a book I got at Target that has a daily log. I am pretty sure that is what convinced the judge of my need for Disability benefits.
 - State Vocational rehabilitation can also help with assessment to resources to documentation for SSDI/SSI. They also can recommend local disability attys
- Is the Power of Attorney the same as a Medical Power of Attorney?
 - Yes, each state has a different name for form.
- Case manager vs. professional caregiver discussion.
 - Case managers can point you to resources but they cannot manage appointments or prescriptions refills. A professional caregiver can do these things but you have to let the person they are speaking to on the phone know that the caregiver has your permission.
 - Medicaid works with specific caregiving agencies.
 - Private professional caregivers can do more tasks than those provided by Medicaid. Galen prefers individuals from care.com because there are fewer restrictions. Care.com also provides background checks on the caregiver. (Galen uses a Medicaid caregiver and a private professional caregiver.)
 - Medicaid will also pay family members to provide caregiving services.
 - Communicate to the caregiver the nature of how much the ill person's function and condition fluctuates.
- "I have special needs and require special accommodations"
 - This is the phrase Galen recommends using when communicating needs with medical offices and hospitals because it triggers the Americans with Disabilities act in their mind. This can be helpful when calling the clinic ahead of time to ask

for someone to push you in the wheelchair from your transportation to your appointment.

Resources

- **Crisis Resources**

- Dial 988
 - [What Happens When You Call 988?](#) (Article)
- Dial 911
- [Crisis Text Line](#)
- [Crisis resource page](#) (BHC)

- **Support Groups**

- BHC Support Group 2nd and 3rd Tuesday at 1 pm MST
 - <https://batemanhornecenter.org/events/>
- Surviving with ME
 - <https://www.facebook.com/groups/695317212152964>
- ME/CFS Social Group
 - <https://www.facebook.com/groups/1202428297198122>
- CFS/ME Friends
 - <https://www.facebook.com/groups/CFSMEFRIENDS>
- International ME Support Chat
 - 11am-1pm EST/ 5 -7pm GMT / 3-5am Melbourne time & 9-11pm EST/ 3-5am GMT/ 2-4pm Melbourne time
 - <https://us06web.zoom.us/j/84362703704?pwd=bfKmegaCLNhS6KwOUve7fkcsQjs7sB.1>
- ME/CFS phone support group
 - Occurs on Saturday nights at 8pm, EST.
 - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
- #MEAction Living w/ME Support Group
 - <https://www.facebook.com/groups/211058135999671>
- Caregiver Support Group
 - <https://www.meaction.net/event/me-partner-caregivers-support->

[group/all/](#)

- Health Stories Collaborative Creative Meetups
 - <https://www.healthstorycollaborative.org/creativemeetups>

- **Transportation**

- In Utah's Salt Lake Valley: The Utah Transit Authority has an A.D.A. Paratransit support system where they will transport you where you need to go, for free.
801-287-2263
- [Easter Seals](#)
- [National Aging & Disability Transportation Center](#)
- [Utah Independent Living](#) Center rents out wheelchairs for free. There are similar agencies throughout the United States.
- [Ability 1st Utah](#) (There are similar agencies throughout the United States.)

- **Communicating Illness**

- Cards: <https://stickmancommunications.co.uk/products/>
- [Crash Survival Guidebook Communication Cards](#) (BHC)
- [Chronic Illness: What I Want You to Know](#) (BHC)
- [Insights into My Chronic Illness](#) (BHC)

- **Disability Resources**

- [Social Security's Policy on Evaluating ME / CFS - Policy 14-1P](#) Social Security SSA
- [Getting Disability by Arguing You Can't Even Do Sedentary Work](#)
- [Navigating Disability - SolveME](#) (video) or [PPT materials](#) For Employer disability plans – SolveME
- [Long COVID & Fatiguing Illness Recovery Program's ECHO](#) gave an excellent lecture on disability
- [Job Accommodation Network](#)
- [Allsup](#) (shared by participant)