

Transcript: How to Be a Demanding Diplomat as a Severe ME/CFS Caregiver

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Description: Galen Warden is the mother of an adult son with severe ME/CFS. Bateman Horne Center partnered with her to provide essential guidance on caring and advocating for individuals with ME/CFS.

In this presentation, Galen discusses the importance of logistics for individuals with severe ME/CFS, how a medical proxy can streamline the process for communicating with medical professionals, types of government-funded disability and tips on gaining approval, tactical advice for transporting individuals with severe ME/CFS to medical appointments, her method for obtaining necessary accommodations at medical appointments, and caregiver support options along with practical management. She also shares her effective communication style when communicating with various medical providers.

Note to community members: We advise viewers to always speak with their medical care team before making any adjustments or changes to their current regimen. Bateman Horne Center's involvement in this program is made possible with the additional support of the Open Medicine Foundation.

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Video Transcript

(Angela) All right welcome to a Bateman Horne Center resource today we are hearing from Galen Warden the mother of an adult son with very severe ME/CFS and so today she's going to talk with us about her experience caring for her son and give guidance for others who may be in this experience as caregivers and as people with lived experience themselves so welcome Galen thank you so much for being willing to be here with us today and share your experience and your expertise with our community.

(Galen) Thank you Angela I'm going to share my screen okay so today I'm going to be talking about the importance of logistics when people have severe ME especially the the logistics can really cause problems if they go wrong some of the things we're going to cover are Medical healthcare proxy power of attorney disability the kinds of disability and little guidance on how to get disability transportation which is so important especially for severe ME how to get to appointments on a gurney or in a wheelchair we're going to talk about accommodations at

medical appointments and this includes getting protection from light and sound as well as speaking to your doctor who might not be familiar with ME and then lastly we're going to talk about caregiver support getting a caregiver the different kinds of caregiving options.

Importance of Logistics for Severe and Very Severe ME

So let's just dive in the importance of logistics can't be overemphasized for severe ME every single detail in these different aspects of care which I call tactical or practical can make a difference and one misstep can lower someone's baseline permanently so you are allowed to be very vocal and very specific about what you need no one else is going to understand the risk that doing this wrong is going to carry for your person or for you so you have to be the one that sort of takes the lead you can be kind and factual educational in your approach but you have to be firm you cannot give the impression that these things are optional it's not optional that your person is protected from sound or protected from you know a bright light shining in their face whatever they have to protect them is for a reason and this disease is neurological so don't worry about explaining what ME is to a receptionist or a nurse or people that you come in contact with the person you know driving the van you don't have to teach them what ME is just say my person has a severe neurological disease or condition a severe neurological condition they are you then you come up with your situation very sensitive to light sound odors so whatever it is that you're trying to explain that they need protection from say it very matter of factly with authority don't be apologetic don't say I'm sorry that you know you could you please quiet down I'm sorry no this is not optional and it's not courtesy it's a necessity it's a medical necessity so if you say they have an extreme neurological condition they must be protected from light and sound and then they're going to see them I mean look at this picture of my son he's got the eye mask and the hat because it's very bright in this room so he's got the noise cancelling headphones and under that he has the foamier plugs so when they see this person come in they're going to say what's going on is really unusual and you don't want to act like you know you don't want to give them any excuse to think oh they're just very sensitive that's not what's going on it's neurological so here they've put James in I asked I went in ahead and I said my son needs to be protected from noise etc is there somewhere quiet and private that he could wait for his appointment well in this particular case they put him in a room that's under construction so they said oh yeah we've got this room in the back so then I go back out to the ambulance and I get the guys to bring my son directly to this special room and they had no problem accommodating us because you have to go in and just be calm and kind and understanding that this is unique and different and you know it's not something that you have to get excited about or get upset about don't be hysterical they'll write you right off their ears will close just be matter of fact and practical about it.

Medical Power of Attorney

Now the first technical legal type of thing that I want to bring up is one of the most important

things you can do I did not know about healthcare power of attorney Janet Dafoe taught me about this that's Whitney Dafoe's mother I didn't have it and anytime I wanted to talk to somebody about my son who is an adult I had to try to explain to them no he can't come to the phone no he can't give you permission to talk to me because he I can't talk to him he can't use a phone you know he was very severe so I got this very simple piece of paper it simply says you know my son's name I appoint Galen Warden my mother to be my healthcare power of attorney you don't need a lawyer this is not financial this has nothing to do with their finances their bank account it's not permission to control anything it's simply permission to have access to all of their medical data and their doctors make appointments find out lab results the simplest things are barred if you don't have this so just get it very easy the image you see on the right is the Utah form which I hunted down because Bateman Horne is in Utah if you go to my website at the bottom of this screen you'll see severemecfs.com/resources and at the bottom of that page you'll see this PDF download it fill it out this one happens to also have advanced directives which is fine to fill out the one in South Carolina does also they don't all some states call it a proxy and in that case they usually don't have the you know directives for end of life etc but whatever your state has very simple fill it out you don't need an attorney you don't you need a couple witnesses that's all you need and then that needs to be provided to every company caregiver transportation people doctor office hospital that you interact with so the first time you go there you hand it to them and ask them to add it to the records or scan it have a PDF and ask you know send it to people say please add it to our record to this person's file so that when you call you can say I have the healthcare power of attorney I'm calling to find out about my daughter son you have it in the file 99% of the time they won't check the file they won't slow you down they'll just say oh okay and they'll talk to you so do this if you haven't got it you might not feel like it's necessary oh they can talk etc doesn't matter you're going to want someone to be able to hunt down lab results etc besides the patients besides the patient.

Disability

Okay disability I've seen so much variety in what people have and what people know about this it's very important to cover the nuances so that's what I'm going to do for you now there are two kinds of disability SSDI is Social Security Disability Insurance the other kind is Supplemental Security Income the first one SSDI is only for people who have worked enough in the US this is all the US to pay into disability so for example you worked for 10 years you made x amount of money and every paycheck a little bit was pulled out for Social Security that money is what we're talking about that's your investment in this insurance plan for disability when you need disability if you become disabled the Social Security Administration will look at your work history and determine how much money they're going to give you based on that work history if you become disabled say you became disabled in 2018 but it takes you until 2020 or 2025 to get your disability going back to that date of when you first became disabled you first applied is the beginning of your disability and with SSDI they will pay you

retroactively they will give you a lump sum for the amount of disability they should have been paying you before you became approved that's really important because that's how you can get an attorney SSDI disability is the only one that gives you attorneys or that attorneys want to help you with if you are looking for an attorney and you you're going for SSDI you have a work history the attorney will give you a contract to sign which says they're going to take 40% of that big lump sum or whatever it is so you're going to read that see what percent they're taking you're going to agree to that you're going to let them work at getting you disability doing the appeal going before the judge if you do a second appeal and you have a court appearance they'll take care of all of that happily because they have a big paycheck coming if you have been disabled for a little while so that's one kind of disability the second kind SSI is for people who have not worked they don't have a lot of money it's really based on the poor people's disability and these people get Medicaid versus Medicare Medicaid covers pretty much everything you need in terms of transportation home health visits doctors hospitals it's good coverage the income that they give you is much less than the SSDI because it's not based on any work history so for example my son gets around \$500 a month he would not be able to live on that it's it's helpful but the real win for him is that his transportation which is \$2500 a trip we'll talk about that later to MUSC our local hospital is completely covered it's free so all of the benefits that come with Medicaid are well worth going through the trouble of applying for SSI now you're not going to be able to get a lawyer there's no back pay the minute you get approved is the minute you start receiving a check the next month whatever so instead of having an attorney anybody going for SSI may appoint a representative this representative could be their parent their sibling a friend anybody can be their representative and once they've assigned the representative that person can fill out all these forms can take all these calls can deal with doctors getting them to do their part for the application so it's a great benefit to recognize that even though you're not going to have an attorney you're still going to have help because it's overwhelming this whole process is very overwhelming most people have to do an appeal my son was bedbound could not even hold a cup of water when we went for disability here in South Carolina and the nurse practitioner that had been helping us from South Carolina house calls coming out visiting James you know doing the GP general practitioner type of work for us she we didn't realize she didn't believe in ME we had no idea I mean here she saw my son every time she came well when she filled out the medical assessment she said that he could walk if he wanted to and I just couldn't even believe it so anyway he was denied I called the disability determination services I said you know why was my son denied he is very disabled and she told me that the person they don't share with you what these doctors write but she told me that the thing that made him be denied was the term he ambulates normally and I said what and she said yes it says on this form he ambulates normally so I called the nurse and I said he was denied disability and they told me you could edit modify resubmit this form so that he can get disability and she said to me I'm not going to modify it and resupport it he could walk if he wanted to and I was so dumbfounded I got right off the phone and of course I was crying and everything but we got a different nurse

practitioner to come and here's what we did I sat down with this woman which I had never done with the other one I was very naive at the beginning don't be naive listen listen to this I sat down with her I had printed out the CDC the different materials on ME I had highlighted with a yellow marker where it talks about the sensitivity to noise and light where it talks about you know the inability to exercise and the extreme debilitating fatigue and the neurological aspect I showed that to her and by highlighting I spared her reading 20 pages but she got the point and when she did the assessment here's what she did she asked James I wasn't in the room she had to do it alone she asked James to push on her hand as hard as he should not as hard as he could and she did the same with his feet push against my hand with your foot as hard as you should without hurting yourself without causing a crash etc based on that the way that she characterized that in her assessment he got it right away and I spoke to the people at disability determination Services who told me he got it within two weeks who told me this is exactly what we need not only did they give it to me in two weeks I got a huge packet in the mail saying that they wanted to put him in a nursing home he was so disabled and of course that's not what we're going to do and I you know I turn that down but that nurse really did a good job of demonstrating his limitations and that's what you need you need those limitations demonstrated in the clinical evaluation whatever it is you want to call it because this is going to be a big part they want their records all the records years of records but this clinical assessment evaluation is going to be key for you because that's today here and now what are his limitations and in the appeal process of course you may end up going to court and sometimes that's the best thing if you've been denied because in court you can really demonstrate in a in a more empathetic I want to say emotional but I don't want you to misunderstand I don't mean you start crying but I mean you're going to appeal to the humanity of the judge and this situation that your person is in so sometimes having to do the third appeal is fine because you will may be more likely to get it you know with a face to face with your representative you know maybe they can see your person for a minute in their dark room you know and then that representative speaks here's the website on the left where you learn about disability and apply there are a lot of links there that will help you get more information if you want to dive into all those and then on the right once you click that blue button on the left apply for disability then you get to the page on the right and on the bottom corner you see SSI and when you click on that you get to information there and in here is the information about representative and these different nuances so it's it's a lot of information and a person with ME especially severe ME I don't think belongs on these websites looking at all this stuff I think you're just going to crash so hopefully you can have somebody look into this for you and get you going.

Transportation

All right transportation is really important you have to get to a doctor appointment or you have to get to a hospital you need a way to get there without crashing without lowering your baseline and James could not sit up we did not know how we were going to get him to

anything when he first got sick I was blind just blind ignorant naive you know going crazy trying to figure out you know he had a seizure he had a 45 minute long non-epileptic seizure from a noise my dog barked outside of his bedroom door and I gave my dog away for three months to a neighbor we you know found out about all these noise cancelling headphones and we did everything to protect him from sound but when he had that terrifying seizure the first thing I wanted to do was get him to a neurologist but you know I didn't know about gurney transportation I didn't know about any of this and I actually tried to get a neurologist to come to our house and obviously that was a the fool's errand so no one was going to come and he never did see a neurologist for that we just started protecting him in any event this transportation is key and doing it correctly with the least amount of stress on your person is really important Medicaid covers unlimited gurney transportation Medicare covers limited gurney transportation but I have to say James only does this four or five times a year in either case a doctor has to say yes this is medically necessary because it's expensive they want to know for sure you're not just on a whim saying that would be nice so get a doctor to give you a letter that you can provide that says it's medically necessary for this person to go to his appointments via medical transportation non-urgent medical transportation you don't want an ambulance you don't want an emergency ambulance besides the siren and the backup beeping and all of that stuff that's not what we're talking about we're talking about going to an appointment not the ER an ambulance an urgent ambulance a 911 call in the US will only take you to an emergency room you don't want to do that that you you're talking about triage and hours waiting and horrible horrible so we're talking now about so James he hasn't walked since 2020 he's constantly getting these ingrown toenail infections and needing surgery on his toenails which is very sad but we need this gurnie to get him to the foot doctor he needed care for his teeth his you know teeth were rotting in his mouth and we hadn't had any dental care for a few years and we needed a gurney to get him to the dental clinic at MUSC where they gave him general anesthesia and did cleaning X-rays fillings and an extraction which was needed at that point all under general anesthesia but had we not had this gurney transportation there would be no way we could have done that so learn about this either Medicaid or Medicare will provide a option for you to get this through some kind of service in your state so with our state South Carolina this service is provided by a logistics company called Motive Care Motive Care is not a transportation company it's a logistics company your state has its own logistics company it might even be Motive Care they're in a few states those are the people that you speak to and that you you know find out what is necessary in terms of you know giving them that doctor letter and they will have a portal where you can talk about the appointment and the time of the appointment and you know all of this where you put in your address and there will be a place for your comments they don't have a box to check for gurney transportation in South Carolina they just say can the person walk you know they have these kinds of questions no no so the comment part is where I put person cannot walk cannot sit up cannot move themselves onto the gurney you know needs a gurney and I put all these details and then that's in the portal it's in his profile so every time we schedule a ride all that

information is there oh he needs a gurney he can't get himself onto the gurney they have to very carefully pick him up and put him on it so use this website here if you have Medicare otherwise work with your Medicaid in your state and go to nonurgent Medical Transport non-urgent you know gurney transportation whatever you want to search in your Medicaid portal for your state and it will get you this information there are private companies and I have used them plenty because Medicaid drivers sometimes cancel so if my son was my son was scheduled for this huge dental clinic I'm talking about he had the dental hygienist the dental surgeon he had anesthesia he had the x-ray people and he had the dentist who was going to do the fillings he had all these people this team of people waiting to see him and his ride did not come 3 in the morning I'm standing out side waiting for this ride because they gave him a very early appointment it's an hour and a half away they never came so I had to learn how to find private people for when this happens and nonurgent medical transport is what you need to look for in your look in your county and it'll be expensive but if you have the Medicare or Medicaid if you have it and if this ride is a approved if you have a doctor saying this is medically necessary necessary they will reimburse you just put it on a credit card that's what I've done three times now I've paid \$2,500 and Medicaid company Motive Care the logistics company reimburses me every single time so that's really good for you to know because you're going to freak out when you see the price for these private you know rides but if you don't have Medicare or Medicaid you know unfortunately it's going to be expensive so I have written a whole piece on gurnie transportation because I was so naive and I had so many problems what you're looking at in this photo is the beautiful aluminum ramp that I had installed I did a GoFundMe and I have you know very generous friends and I was able to do this because otherwise this expensive and heavy metal gurney was being for about two years carried down my front steps five steps these people were complaining you know this is too much this is too heavy you need to get a ramp so I went ahead and got it and you know hopefully one day my son will be you know strolling down that in a wheelchair again so that's my personal you know journey but I've got a whole thing on the gurney and how to get the transportation and all that on my website in a blog post and there's a PDF you can download called the gurnie guide and it's gotten a lot of great reviews people saying how much it helped them and how much time it saved them to know all this.

Accommodations at Medical Appointments

All right you're at the appointment or you're making the appointment even and you want to be able to prepare the guy who's doing the toenail surgery or the dental clinic or the these you know whatever appointment you're going to you're going to get a CT scan you're going to get an MRI you want to speak to these people before you go and say my person has a severe neurological condition you don't have to talk about ME as I said earlier your job is not to explain what the medical system and social safety net and hospital whatever education has failed your job isn't to make up for their failure your job is to protect your person so rather than being upset that nobody knows what ME is just take a breath and say my person has a

severe neurological condition and needs special accommodations use those words special accommodations are the way to talk about disability and we have the Disability Act in the US and that act says that medical providers doesn't matter who they are they have to accommodate your disability and the inability to tolerate sound and light neurologically even if your person has never had a seizure this is in their brain this this damage is being done in their brain it's not a matter of their eyes or their ears it's their brain it's so important so if you say to them this is a disability accommodation we need say it very nicely don't get upset and excited I can't emphasize that enough I have seen the doctor notes when I helped somebody with severe ME their mother didn't speak English I was the actual proxy for them in their state I talked to the doctors I arranged all these things for them I helped them a whole lot well well I saw the notes from an appointment and do you know that about 10 times in those notes the doctor said the mother was very upset now that's not helping the patient the doctor needs to focus on the patient so calm yourself take a breath prepare yourself mentally okay they don't know about ME that's all right all that matters is that they take proper care so go in and say neurological condition they have they need special accommodations for light and for sound these little pieces of paper you see in my bunny calligraphy whatever are actually pretty big and I put them on him this was early in our journey when he had an MRI because they were going to give him general anesthesia for the MRI you can't tolerate you know boom boom boom and I they told me they assured me they would put his headphones back on before he woke up etc but anyway I put these notes on there and I tried to you know help them help him and it all went very smoothly but try when you talk about all these things try to think about everything that could possibly go wrong and address it for example holding supporting his head they're not used to transferring someone onto a gurney who is as disabled as James is that's not paralyzed he's not paralyzed he they see him moving his hands they see him you know there's something kind of normal about him what's going on but he can't hold his head up so they have to put the transfer sheet under his pillow you know and move him carefully not jerk him you know all of this and I I talked to them about this before we even you know get into the van I talk to the drivers about it but once you're at the medical appointment if there is any transfer happening such as with an MRI or a CT scan where they have to go on the special bed just explain to them you know how to handle your person whatever it is that they need the second thing is if it's an office and not a hospital you can go in ahead and leave them in the transport go to the receptionist and if you hear you know Kenny Loggins or whatever he is you know saxophone playing or whatever ask her to please turn off the music during your son's visit she might make a face she might shrug her shoulders don't worry about it just be nice and they will always do it you know my my person is very sensitive to sound would you mind turning off the music while we're here in the office and you're saying that at the same time you're asking for the special waiting area possibly somewhere dark my son when he gets his toe surgeries has his own room because they're used to him now so when I make an appointment they look for a day that that room is available for his surgery and so they're very familiar but you know always try on the phone and then again repeat it when you get there

say you know we need a quiet place to wait or should he just wait in the van which we also do and then you know he comes in right when he's ready to be seen so all of this should really help you to avoid stressing your person out exposing them to

harms now if you have a doctor a general practitioner someone important not the pediatricist or you know an ancillary comorbidity person that you can just say they have a severe neurological condition to if your doctor regular doctor needs to know about ME you have to do a little more to educate them this is similar to the way I sat down that nurse practitioner who came to my home and educated her I printed out the CDC materials I highlighted Etc so here are some little basics for you in 1969 the WHO classified myalgic encephalomyelitis (ME)

neurological disease they used that word so we have a history of the medical profession knowing this is a neurological disease well then in 1989 some psychiatrists got a hold of it and renamed it chronic fatigue syndrome CFS unfortunately this nickname really stuck and it's easier to say people don't know the acronym ME so people very often say CFS people are diagnosed with CFS doctors say oh yeah I know about CFS doesn't mean that they understand the neurological disease it means that they know the person is tired so you do need to educate them yes ME is the same thing but but there's much more to it we say ME/CFS my website is severe ME/CFS because of the way CFS is ubiquitous I mean people know it so you kind of have we're kind of stuck with it but we can add ME to it to clarify and you know make sure they recognize that's this is what we're talking about it's not just being tired like you a condition or anemia or you know lupus or other things that give you fatigue this is overwhelming exhaustion post exertional post exercise collapse to complete inability after an exertion this person can do nothing they may be in bed stuck in bed for two weeks if they are you know forced to exert themselves a harm in harmful way here's the diagnos diagnostic code for you G93.32 this is important because it's new since last October and doctors don't necessarily have that diagnostic code so it's good to provide it especially any new doctor if an old doctor has the CFS code which is generalized fatigue of unknown origin or something like this they may not be willing to change it but any new doctor you can provide this code to them and say yes this is what they have and I've never had a doctor say oh let me see the doctor notes of his diagnosis I've never come across that but if you say he's diagnosed with ME and here's the code a new doctor you know someone dealing with their heart or different you know aspects versus the actual ME specialist will accept it so according to the CDC 90% of people with ME do not have an official diagnosis think about that so your doctor cannot be blamed for not knowing about this they weren't taught about it in medical school Mount Sinai in New York City has just started the very first for them the very first course on complex diseases which includ includes long COVID and ME so we're making progress it's changing because of COVID and post infectious ME from COVID now if your doctor is familiar with long COVID simply explain to them oh that's fantastic so you know about ME my son has long mono instead of getting it from COVID he got it from the Epstein bar virus so this is the way

to help them sort of process this and get the idea if they're familiar with long COVID which many many doctors are now there's just millions of people that have it I heard recently 3.3 million in the US have long COVID so this is ridiculous it's insane what is happening so the [cdc.gov/me-cfs](https://www.cdc.gov/me-cfs) is the government's you know page on ME and it goes over ME the symptoms how to diagnose it and everything so this is really helpful to your doctor.

Caregiver Support

Regarding caregivers I would say that everybody with ME especially severe ME that is being cared for by a spouse or a parent also needs supplementary additional caregiver support I say that because this disease is overwhelming for both the patient and whoever is taking care of them and everybody has to get a break even if the parent says I can't trust anybody else or you know I can do it I'm here I'm not working or whatever doesn't matter there is going to come a day when that person burns out and feels so overwhelmed and has some kind of an emotional you know outburst of some kind because it's just too much and you can avoid that from the beginning by making sure whoever is taking care of the person can get away you know take a day off get a massage talk to a therapist whatever they need to be supported themselves this is trauma trauma for the patient to have their life you know pulled out from under them and trauma for the caregiver because the caregiver is also losing their life in one sense and that is their freedom I care for my son he's bedbound if he drops his mouse he can't pick it up if he needs water and he doesn't have any water he can't get it himself so my life is as restricted in a way as his is and this is a trauma for ME so I at the very beginning I had psychologist help me which was fantastic and helped me deal with my past trauma so as a caregiver I was being triggered I really don't like that word but I was being triggered by my son's criticism of me so if my son said you know if I had to rub his shoulders if he said I was doing it too hard or not hard enough or I was tickling him or if I was trying to brush his teeth which was so difficult to do and he would say you know you missed a tooth why do you always do this and why do you always do that you're going to make me throw up and you know these criticisms sent me at the end of whatever we were doing and I closed that door quietly and left his room sent me running to my room crying because I was so upset at being criticized well I'm trying doesn't he know I'm trying I'm doing my best you know and therapy helped me understand what was going on with me this had to do with my past and when I was able to get over my past trauma the things that had to do with my personality now I'm like okay you know I won't do it so hard or oh I'm sorry I tickled you or whatever you know in my mind this is the conversation I'm having I'm not having a why is he criticizing me conversation anymore I'm having a oh that's easy to fix that's what I say now oh that's no problem and instead of walking out of his room and crying I'm walking out of his room and checking my email you know it's there's no emotion attached to it anymore and I can't emphasize enough getting support for everybody involved is absolutely key to success with having someone especially severe or very severe ME so Medicare gives you caregivers not just Medicaid and this is where you go to see them home health services means someone that's going to come into your house take care of your person

the way that you direct them to and they may not see how it says health services it doesn't say home services they may not want to do laundry or cook or do dishes and things like that that you really need help with some people just want a babysit they just want to sit in the room like they do with somebody with Alzheimer's or an elderly person in hospice etc where if you have an 85 year old who needs you know care they love to have somebody sit there and chat them up and have a visit etc somebody with severe ME can't tolerate even someone's presence in their room let alone somebody chatty so when you start this journey of getting a caregiver write down these needs the need to be calm quiet minimize talking all of these things say all of these things in a way that you can develop a profile that you provide to any caregiving agency whether it's Medicaid Medicare or private this profile that you construct with these requirements of behavior can also include assistance with laundry preparing food I mean for me it's even cooking food cleaning you know lighthouse work etc I include that and I have that and it took me a while to get it I had to go through several people that just wanted to sit on the couch and look at their phone if my son didn't need them and you know that that just wasn't helpful enough so do what you can work with people people be kind when you have these services Medicare or Medicaid get a case manager everybody doesn't have one everyone doesn't know that they exist ask for a case manager this is like a go between this is a person who can guide you regarding these services and everything from you know providing the links to get the transportation to giving you options for caregiver agencies that work with Medicare or Medicaid so you can say you know I need somebody that's going to help in the kitchen or help with laundry and light house work I really need help I'm overwhelmed taking care of this person 24/7 I need you know more support than just being with them you know try to explain it and they'll direct you to an agency that's more likely to accommodate your needs now the other thing so important especially with Medicaid is that these people are not paid enough my person that was working for me was getting paid \$10 an hour in South Carolina if you can imagine you know cleaning someone who poops in their bed a giving someone a bed bath taking care of someone with these extreme needs for \$10 an hour it was almost impossible to get someone good if you're able financially to tip them over and above whatever you find out the agency is paying them you know you can do that to if you find out someone is good so the way that I approached it was if I like somebody if they're doing a great job if I want to keep them I tell them you know what I could really use help with x y and z do you mind if I give you a little cash or if I pay you a tip or whatever so that while you're here you can do more than the things on your list because you know they're given a list depends on your state but they're given a list of what they're allowed to do so these kinds of conversations are absolutely necessary for severe ME our government our medical institutions the way that all of our health care system is set up is not set up to accommodate the extreme needs of our patient population so you have to be creative think outside the box bend the rules whatever you want to call it to get the support you need so that you can be healthy if you're the caregiver and that way you can provide the best care for your person I have created a binder I call it training materials on my slide here and I have an interview with the person I show them

the binder I talk about this is how we do the food or this is how we do you know the different things how they need physical help if they have to roll over you know whatever it is that your person needs be very detailed in this binder and give them something to sort of look at and determine you know is this something I want to tackle because you don't want to get somebody in there who is going to be there for a day or two and then just not come back ghost you I have been ghosted God there's nothing more frustrating you know it's enraging really that they don't have the courtesy to say I'm sorry I can't make it but you know people don't do that these days they just will not come when they said they would come so try to make them really prepared and then the second thing is tracking and tasks I have a binder that has information for people who come and take care care of my son I have a page blank page for every day that someone comes I put a list okay today we need to you know do XYZ you know take out the garbage you know whatever whatever bed bath you know something that might be on the list for the day they the person who's helping you will check off things as they do them and will write in things that they do for example at 10:30 they had toast with cream cheese or you know whatever it is that they want to do for you do not let this person whoever they are do not let them handle the medication you can let them give the medication but you have to be the one period no exceptions the caregiver or the person with ME has to be the one to put those pills in the dispenser so on Tuesday at breakfast these are the six pills on Tuesday at lunch these three on Tuesday at dinner these four they get from the prescription bottle into that dispenser by you or the patient don't trust anybody else to do that it's really important and I I just brought that up because this tracking they would say you know I gave them the pills with the lunch so you know we use these little red cups and we put the pills in the cup and they bring the cup with the food and you know so that's you know I hope I hope that covers your questions regarding care.com is the source that we use to find private care before we got Medicaid now I know this is this is from Terminator 2 she is fighting for her son and that's what you have to do you have to fight for your person now that does not mean as I said before screaming yelling and crying and you know being emotional but it does mean being authoritative you walk with some swagger you go in there and you say you know this is what we need this is why we need it extreme sensitivities etc and don't back down don't compromise on something that's really important for them so take care of yourself take care of your person with this kind of attitude like you know what I am fighting for their life and that's really what you're doing because you know you're going to be the one if they go from being housebound to being bedbound because of one visit you're going to be the one who suffers not that doctor where is that doctor that told me to send my son to a psychiatrist when he stopped walking he I tell you what he's not doing he's not sitting by my son's bed holding a cup of water so he can sip from the straw that's what he's not doing so you are the one that will suffer the consequences you and the patient and so don't don't budge an inch on something that you know is really important that you need so here's my son before he came bedbound he only had about three or four months in this beautiful electric wheelchair with the joystick and the headrest he quickly became bedbound because we had been ignorant this was the this we

bought this about a week after he got his diagnosis and we realized he wasn't going to just spontaneously get better before we knew about ME we thought oh you know yes he's getting worse but since the doctors say he's okay he'll just get better you know anyway so here is more information I have a website these two URLs galenwarden.com and severemecfs.com both go to the same site it's just a redirect and you will find my blog and a link to my TikTok where I have a lot of educational videos and the gurney guide is there there's a blog post about caregivers and you know hopefully you can get ahead of all of these logistics and not be like I was where everything was new to me and I had no idea what I was doing it was the worst it just stressed me out so much so hopefully this has been helpful and you get the care that you need the way that you need it. Thank you so much Galen for that that was an incredible presentation with detail and guidance and we know that our community will greatly benefit from your experience and what you're willing to share we really appreciate you and it's with people like you that make Bateman Horne Center who we are that we're able to provide these resources and do the work that we do so thank you for that. Thank you it was a pleasure.

Resource Links

- [Healthcare Power of Attorney](#)
- [Apply for Government Funded Disability](#)
- [Medicare and Medicaid Non-Emergent Transportation](#)
- [Galen's Gurney Guide Blog Post](#)
- [CDC Website for ME/CFS](#)
- [Medicare Home Health Services](#)
- [Galen's "You Need a Caregiver" Blog Post](#)

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