

October 9, 2024 WOW Meeting Notes


Today's Topic (and November's topic):

- After a move: Adjusting to a new environment, including costs for personal care needs, and instrumental ADL's such as housekeeping,.
- We'll also discuss finding new doctors,. making new friends, and acclimating to a new social life.

Our Advertisements 😊:

We reminded all that we are a group of women who share a common bond of having FSHD. We speak openly with each other, however we maintain confidentiality of the information which is shared, as this is a request of the group members. Notes are taken, and de-identified, so that others may benefit from the collective intellect and experience of the group members.

Please don't forget our booklist which is wonderfully managed by Laura at:

 [WoW Member Book Recommendations](#) .

- We have a FaceBook page to continue our conversations or ask questions of this great community. Only women with FSHD are admitted. Please use this great resource found at: <https://www.facebook.com/groups/fshdwow>
 - We do want as many in our community (Women WITH FSHD) to join this group. Share with others who meet the criteria.
 - **If for some reason you can't share and you know of someone who meets the criteria PLEASE reach out to me, we can talk it over and see if we can add them.**
- Remember the Society has many different Gathering Groups, i.e. Feeling Fit, University, Wellness Hour, Straight Talk radio, Area Chapter meetings, Early onset, Young Adults, check out the calendar for information on when they meet and the topics for the month. <https://www.fshdsociety.org/fshd-events-calendar/>
- Importance of sharing your voice AND VOTING! This is a *very non-partisan* request.
 - It is so very important to vote! Here is some information on Disability Voting Rights <https://www.aapd.com/voter-info/>
 - Voting is a way to live a self-determined life by influencing the people and policies that affect your everyday life. Your vote can help create a positive change.
 - If you want to know what you will be voting on in your district go to this site: vote411.org also this one has good easy to obtain information: https://mdaaccessthevote.org/?utm_source=sfmc&utm_medium=email&utm_campaign=September+Monthly+Newsletter_09.06.24&utm_id=891803&sfmc_id=47926328&referrer=September+Monthly+Newsletter_09.06.24+sfmc
- The 2025 topics survey will be available at the end of December 2024 or early January 2025
- If you don't receive the reminder email about our WOW Meeting, from the Society. Please let me know, I have a list of folks I automatically send the reminder out to. I am happy to add you to the list.

Here we go with our notes from this great meeting.

We heard from a member who has recently moved. The move has been challenged by the loss of several family members. She shared, as a person in a power wheelchair, she has had many challenges in being about to maneuver around her new home and her new community. She has learned how to hire caregivers, rides to appointments, to the grocery store or running errands. She is very rightly proud of herself for all that she has accomplished and overcome. She figured out how to hire caregivers, drivers, and a “girl friday” to help her live her best life. **YOU Go Girlfriend!!**

One of our members had a very providential experience... she was in a parking lot, struggling to put her purchases in her trunk. She heard a voice behind her saying... *I help you*... she did accept her kind offer, and moving forward...she is now helping out our member on a weekly basis at a minimum. This woman is an immigrant from Ukraine, a nurse, who is trying to get licensed to be a nurse, again, here in the US. She helps with all kinds of housework, shopping and helping our member and her family. The wisdom behind this story is we never know where the assistance we need may come from. What many of us heard in this story, is the “gut” instinct our member had that this woman was a good, kind woman.

We heard the question... how do you hire help for personal care needs? This is what our members shared with us.

- There are agencies to call (A Place For Mom, Home Instead, Visiting Angels are only a FEW of the many) they will provide background checks. Many reminded of the importance to do your own screening, be an advocate for the background screens and for what is specifically important to you!
- Care.com is an option, they do a limited background search in the free version.
- One member reached out to her neighborhood social media site, with a very positive outcome!!!! Her new caregiver is helpful with getting her out of bed all the way to household needs.
- A ceiling lift is an option. We heard of a company called Surehands <https://www.surehands.com/> it is but one company and option. These devices may be able to help us provide for our own care needs... they may not. It is important to identify *what you need, what is important to you, what you can afford to pay.*
- One member shared she has a long term insurance policy that allows her to have a personal caregiver, and help with household care needs. It allows her to feel more involved and engaged with her family and family care needs.

Long Term Care Insurance, our thoughts, our comments

- We heard from a couple of members who shared IMPORTANT information
 - They were able to sign on to a Long Term Care Insurance Policy **through their employers**, there were no concerns about *pre-existing conditions*.
 - We heard, loud and clear from our members, if your employer offers a Long Term Care Insurance policy to CHECK it out!!! Do not automatically dismiss it, thinking you won't qualify... YOU DON'T KNOW YOU WON'T QUALIFY UNTIL YOU CHECK IT OUT, READ THE INFORMATION CAREFULLY.

- We also heard, from members who had these Long Term Care (LTC) Policies, question when to start to use them.
 - We heard our members with these same type policies, **to** start to use them. It will help them tremendously, we heard them say that using the policies will help them emotionally and physically as they maneuver throughout their days.
 - A member's family member had a LTC policy that has helped them tremendously. The member learned how to ask for help. How to phrase the needs so that your helper/caregiver will better understand you.
 - Also noted in this conversation. The importance of keeping your cool when your helpers don't provide the assistance you WANT in the manner you wanted... but respond in the manner in which they heard the request. Our helpers are human, they assimilate information as they hear it, in their own brain and personality... then you see the outcome of all of that. Our helpers want to do their best, and to help us as best they can. Communication and patience is so important.
- We are reminded that if your husband was in the U.S. Military, as a wife of a honorably discharged veteran you may be able to obtain assistance through the VA. Please note, as the child of an honorably discharged veteran, there are special circumstances where *you may* qualify for services. It is always important to check out for these possibilities.
- From the Resource List (below): Veterans Affairs- they have resources for spouses and widows, possibly for children of veterans.

Important links to check out:

 - <https://www.va.gov/health-care/eligibility/>
 - <https://www.va.gov/health-care/eligibility/active-duty/>
 - https://discover.va.gov/external-resources/?_resource_type=state-veterans-affairs-office
 - <https://www.va.gov/find-locations>

We heard mention of *ableism*, we heard that many of us were not familiar with the term. The Oxford Dictionary defines ableisms as: discrimination in favor of able-bodied people.

- We heard that many in our group would like a session dedicated to the topic of Ableism

We heard that aluminum is something we should not be using a good bit of... it can be in deodorants/antiperspirants. We also know that we often use aluminum when cooking to help with clean up. We heard parchment paper works just as well, and is not hazardous to our bodies. You can also buy parchment paper that will fit into roasters, air fryers and pans!!! Makes cleaning up easy!!

Our next meeting in November (1st Wednesday of the month 2p PT/3p MT/4p CT/5p ET) we will continue our discussion on today's topic:

- After a move: Adjusting to a new environment, including costs for personal care needs, and instrumental ADL's such as housekeeping,.
- We'll also discuss finding new doctors,. making new friends, and acclimating to a new social life.

Below is the Resource list as it is today. Please remember it is a *living document*. I add new resources as I come across them. To get the latest version...Here is the link:

https://docs.google.com/document/d/16-PzewRI5Cd1g05rUyBoO_QxLCmDwZDL7OcM_3d6jAl/edit?usp=sharing Trouble opening, don't hesitate to reach out to me!

Resources that might be helpful, many of these resources come from many organizations we may not have thought of as they focus on different illnesses and some different physical challenges ... Please don't rule out these potential organizations or government agencies, to help you. The agencies I've contacted, shared, they help all that they are able to... it is not purely dependent on the reason for the disability.

1. United Spinal has many great resources:
 1. Grants via United Spinal
<https://askus-resource-center.unitedspinal.org/index.php?pg=kb.page&id=2971>
 2. United Spinal has great information e.g. Best tips and strategies for finding and hiring PCA's and What we want our caregivers to know, found at:
<https://unitedspinal.org/advocacy-resources/>
 - a. <https://unitedspinal.org/best-tips-and-strategies-for-finding-and-hiring-pcas/>
 - b. United Spinal Association's **Care Support Webinar: Finding, Hiring, Training, and Retaining Care Support Professionals** provided the opportunity to listen to advocates share their experiences, suggestions, and resources to help find ways to navigate the caregiving crisis and how they manage their own care. Also, care support professionals discussed what they need to provide the right care supports for their clients, and Nancy Taylor, Senior Policy Advisor for the Administration for Community Living (ACL), discusses a few of the many efforts being done to impact the care infrastructure and the services and supports that people seek. <https://unitedspinal.org/care-support/>
 3. <https://www.benefits.gov/> is a site to search for benefits you may qualify for from the US government. Please give this one a try, and put your tax dollars to work for you!
 4. Veterans Affairs- they have resources for spouses and widows, possibly for children of veterans.
Important links to check out:
 - a. <https://www.va.gov/health-care/eligibility/>
 - b. <https://www.va.gov/health-care/eligibility/active-duty/>
 - c. https://discover.va.gov/external-resources/?_resource_type=state-veterans-affairs-office
 - d. <https://www.va.gov/find-locations>
5. Our Federal Tax Dollars fund the Area Agencies on Aging (AAA)... just like Medicaid, each state uses these dollars differently. However it is always a good idea to call your local Area Agency on Aging (Google area agency on aging and your state and county) and find out what they do and don't provide... I believe you might be surprised (at least that is always my hope!).
 - a. Most AAAs are direct providers of Information and Referral/Assistance, case management, benefits/health insurance counseling and family caregiver support programs. <https://www.usaging.org/Files/LocalLeadersAAA2017.pdf>
6. MDA has some resources that can help us navigate our journey's:
<https://www.mda.org/care/resource-list> and
<https://www.mda.org/care/mda-resource-center>
7. The Christopher Reeve Foundation, has many different resources, which can be accessed here: <https://www.christopherreeve.org/todays-care/>

8. The MS Society is also a wealth of information:
 - a. Finding Doctors
<https://www.nationalmssociety.org/Resources-Support/Find-Doctors-Resources>
 - b. Emotional Support
<https://www.nationalmssociety.org/Resources-Support/Find-Doctors-Resources/Guides/Emotional-Support>
 - c. Guide to Home care and Housing
<https://www.nationalmssociety.org/Resources-Support/Find-Doctors-Resources/Guides/Home-Care-Housing>
 - d. Guide to Independent Living Resources
<https://www.nationalmssociety.org/Resources-Support/Find-Doctors-Resources/Guides/Independent-Living>
 - e. Guide to Mobility and Accessibility
<https://www.nationalmssociety.org/Resources-Support/Find-Doctors-Resources/Guides/Mobility-Accessibility>
 - f. Increasing Accessibility in the home
<https://www.nationalmssociety.org/Living-Well-With-MS/Mobility-and-Accessibility/Increasing-Accessibility#section-1>
9. For our Canadian friends:
 - a. Choices in Supports for Independent Living
<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/choice-in-supports-for-independent-living>
10. Independent Living Centers:
<https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>
A bit of information on the philosophy, history and laws that initiated the concept:
[Philosophy of Independent Living](#) AND [History of Independent Living Centers](#). .
11. Patient Advocate Foundation- Their mission is to provide patient services, eliminating obstacles in access to quality healthcare.
 - a. Navigation Tip Sheet
<https://education.patientadvocate.org/resource/navigating-assistance-programs-finding-help-tip-sheet/>
 - b. Education Resource Library <https://education.patientadvocate.org/>
12. Information on loans to make property improvements on Title 1
https://www.hud.gov/program_offices/housing/sfh/title/title-i
13. Forbes article on affordable housing:
<https://www.forbes.com/health/senior-living/affordable-housing-for-seniors/>
14. Disability Information and Access Line. (DIAL) A U.S. government site. This site has information to help individuals with disabilities get connected to information about local community resources that promote independent living. <https://dial.acl.gov/home>
15. Elcercare Locator, a public service of the U.S. Administration of Aging, to connect you to services for older adults and their families. <https://eldercare.acl.gov/Public/Index.aspx>
16. National Council on Independent Living (NCIL). Has a mission to advance the disability-led independent living movement to expand the capacity of Independent Living Programs to enhance the human and civil rights of all people with disabilities.
<https://ncil.org/>
17. <https://www.ilru.org/> (Independent Living Research Utilization) program is a national center for information, training, research, and technical assistance in independent living. Its goal is to expand the body of knowledge in independent living and to improve utilization of results of research programs and demonstration projects in this field. It is a

- program of TIRR Memorial Hermann, a nationally recognized medical rehabilitation facility for persons with disabilities.
18. <https://www.careyaya.org/faq> An organization matches college students with individuals in need, unfortunately not available in all states., There are specific care needs that are not included, but many needs are. Always worth checking into.
 19. <https://www.ndrn.org/> NDRN ensures that Protection and Advocacy Systems/Client Assistance Programs remain strong and effective by providing training and technical assistance, and advocates for laws protecting the civil and human rights of all people with disabilities.
 - a. Or Google Disability Rights for your own state for more information specific to your locale.
 20. National Center on Health, Physical Activity and Disability <https://www.nchpad.org/> Great resources <https://www.nchpad.org/resources/> This group's goal is to build healthy inclusive communities.
 21. <https://gatheringstrength.org/> to help with exercising to gain the best version of your life. Online exercises for individuals with disabilities
 22. PAN <https://www.panfoundation.org/> Their Mission: We accelerate access to affordable, equitable healthcare through financial assistance, advocacy, and education.

An interesting article on family caregiving from USA Today and AARP: [Family Caregiving](#)

Also there are different prescription discount cards. GoodRX (<http://www.goodrx.com/>) is one and the one below... but remember there are many available. Use your browser (Google) to find more.

 <p>DRUG DISCOUNT CARD</p> <p>BIN: 019520 RX PCN: NMeds RX GRP: DRUGCARD ID: NMNA733663784223</p> <p><small>This is a drug discount program, not an insurance plan.</small></p>		<p>NeedyMeds Drug Discount Card www.needy meds.org</p> <p>Patient: Simply present this card to a participating pharmacy to receive a discount on your prescription. Patients who have Medicare, including Part D, Medicaid or any state or federal prescription insurance can only use this card if they choose not to use their government-sponsored drug plan for their purchase. The card is not valid in combination with those programs. For questions concerning the card, call 1-888-602-2978 or visit www.drugdiscountcardinfo.com.</p> <p>Pharmacist: Card must be presented to receive program benefits. Clear system of prior cardholder information associated with this universal cardholder ID. For processing questions, call DST Pharmacy Solutions at 1-866-921-7286.</p>
		

- Save up to 80%
- Use at over 65,000 pharmacies nationwide including all major chains
- Share the card with friends and family
- Use the card as often as needed
- Free, no fees or registration
- Never expires

