

8/7/24 WOW Meeting Notes- 18 Participants

Our **topics for September 4, 2024** are:

- Making and keeping friends, especially if homebound or if friends move away
- Coping with jealousy of able bodied women

Our **August topics: A smorgasbord of topic opportunities!**

- The types of providers we use to take care of our unique needs
- Managing fatigue
- How to maintain a sense of humor when life isn't so funny

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

 [WoW Member Book Recommendations](#) .

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.

Pre-meeting information and discussion:

- The FSHD Walk and Roll season is getting started. Our group could have their own virtual team!!
  - We are in need of a Team Captain for our virtual Walk and Roll Team. Please let me know if you are able to provide for this need.
  - ***We could use this opportunity to honor our WOW friends/members who are no longer with us (Erin, Susie, Karla)...*** Please let me know what you think. We could do this by donating to Nuss Fighters, in honor of Karla at:  
<https://give.fshdsociety.org/team/600484>
- 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/>
- If you missed the great University on "Better Nutrition, from Selina Lai, I believe this link will provide the recording of this great presentation :  
<https://www.fshdsociety.org/fshd-university/#Playlist>

On to today's topics: **A smorgasbord of topic opportunities!**

- The types of providers we use to take care of our unique needs
- Managing fatigue
- How to maintain a sense of humor when life isn't so funny

We started off with the topic on **Providers**:

- We heard of a new service via an app. This service is for **Physical Therapists** to come to your home. **It is called Luna**. It was recommended to our member from her Physical Therapist employed at Johns Hopkins. Her insurance covers this service. She was interested in stretching exercises. They also gave her suggestions about problem areas in her home, e.g. putting blocks under her table legs to make it easier to use. Below is the website.

#### [Luna Program Physical Therapy](#)

- You can also call at 866-932-1961 or access via <https://www.getluna.com/> . There are a limited number of visits per insurance, always be sure and check this out, be a prepared consumer.
- A member wondered if via her Medicare Advantage plan, a nurse would be required in the above new care plan. Please check with your insurance coverage before initiating a program such as this.
- That brings us to questions about Medicare Advantage versus Straight Medicare.
  - This is truly a personal question, it is not a one size fits all decision. Think about your personal health care needs, including treatments needed, medications you are on (does the plan cover your current medications?). What are the out of pocket costs involved with the Medicare Advantage plan you are investigating? Do you live in a rural environment, always assure a potential Medicare Advantage program is in network with the services in your community, including services you don't need now, but may in the future (e.g. A Skilled Nursing Facility, Labs, hospitals, Diagnostic facilities to name just a few).
  - Here are a few sites that have great questions to ask yourself when wondering about what program would be best for you (Medicare Advantage vs Medicare)  
[Medicare Advantage vs Medicare by Goodrx](#)  
[10 Facts about Medicare by Medicare Hero Advantage](#)
- Many folks on Medicare are not aware that you would probably qualify for a Home Health Maintenance program for your Physical Therapy needs. This has been around for a long time, and still a great resource for Medicare Rehab via Home Health Maintenance Therapy benefits. You need to be considered Homebound by Medicare regulations.  
[GUIDELINES FOR PHYSICAL THERAPISTS TREATING CLIENTS WITH NEUROMUSCULAR DISORDERS](#)
- Please also watch the August 22, 2024 Feeling Fit for a presentation from a Home Health Physical Therapist, who discusses the benefits from [Home Health Maintenance plan](#) (on the FSHD Society YouTube channel).
- Another member shared what she feels are great experiences with her Medicare Advantage plan. Her Physical Therapy program was not in network, she switched to a new Physical Therapy agency (in network) who didn't understand FSHD, however they were receptive to her suggestions specific to her needs.
  - She reminds us of the importance of advocating for your specific needs related to FSHD, educating new providers (of all types).

- Another member reminds us when starting a new therapy, not to over do the exercises. Being sore from new use is one thing, being in pain from overdoing it is another... if it hurts you don't do it!!!
- The Society has provided excellent pamphlets we can share with new providers: [Recently Diagnosed with FSHD?](#) [Our new Physical Therapy brochure](#) [Symptoms Health and Medicine](#)  
Find these and many more great brochures to share with your providers, family and many others at <https://www.fshdsociety.org/page/2/?s=PT+for+FSHD+brochure>
- **Neurologists**
  - One member lives near a teaching hospital. They have a clinic with medical students who are eager to share what they know, and learn from patients on topics they don't know about.
    - She encourages us to look at a teaching hospital for our health care needs.
- **Physiatrists** (Rehabilitation Medicine Provider)
  - A couple of members see a physiatrist for their FSHD care needs. For one member it took a couple of tries to find a good fit. The first one was not interested in learning more about the disease. Her second physiatrist has been wonderful. Identified a need for a power wheelchair and set up for the necessary next steps into getting one. The new physiatrist has helped her attain a home health aide for personal hygiene needs... This has had its trials, with the shortage of home health aides, she is not always able to have an aide come weekly as prescribed. However, when she is able to get a home health aide (female), it is a win-win!
  - The second member feels like she hit the jackpot with her physiatrist. She is well informed, quite up to date with the latest clinical trials, and quite aware of the problems/concerns related to FSHD. When she shared that her head was getting heavy and her neck was having trouble holding up her head, this provider actually listened and tried to problem solve with her!!! Quite a different response from the last provider who would merely shake their head to acknowledge the concern!!! Mercy!!!

Next big topic is **having a good sense of humor-**

- One member giggles when she gets to an event, where folks are looking for chairs to sit in... she likes to share with a smile on her face... she brought her own chair!!!
- Many spoke of the need for compassion and self-compassion. Not only for ourselves but for all of those around us.
  - Giving ourselves and those around us grace....It provides us the ability to experience the range of emotions that we deal with on a daily basis. It makes it easier and a bit lighter for us to get through our tough days, and appreciate the lighter days.

- Life is complicated, probably for all of us, allowing compassion to flow organically doesn't have to be a challenge, following this philosophy helps grace to flow naturally through a multitude of situations.
  - One member was a valuable contributor on this important tenet. Thank you!
- We heard that if we make the joke about a potentially stressful situation **first**, it does make the situation lighter.
- Sometimes we feel so many things at once, especially in a new or stressful situation. We heard that asking for assistance doesn't need to be serious or painful, a bit of humor in the ask helps you and the person you are asking for help. "Talk to your people about what you need".
  - To this topic we heard that we would be very willing to help someone else in need... giving this option to someone else is also a gift. Life is such an adventure, usually the dull moments are far and few between...we help the situation by adding a bit of humor and levity!!
- We heard that someone has a "*humor bug*"! She encourages those around her to catch it!!! What a great idea!

Next topic is **Fatigue**

- A traveling member was looking for help in her temporary location. She searched on Care.com and found a temporary helper!!! She is thrilled with the great help, she also mentioned her new helper has a great sense of humor, our member is so grateful. Great way to think outside of the box!!! The new helper has been a tremendous help to fight her fatigue!
- We listened to different ways/manners of pacing ourselves. Don't over do it! Getting too tired can make us crabby/irritable... not a fun happy place to be in.
  - Soooo take a nap!!! We learned that many of us take a nap!!
  - One of us has a special reclining chair... it has a name.... *The most wonderful place on earth* chair. Naming our special adaptive helpers is a big emotional help!
  - A couple of us curl up in our bed, put the BiPAP on and get a great nap!
  - Listen to your body, is it in pain, tired or fatigued? Maybe it needs a nap and a slow down.
  - We heard that the recline function and leg lift function on our power chairs makes our wonderful chair a recliner... on the move so to speak!
- We are reminded of beautiful words shared by Isaac Prilleltensky, PhD: **You Matter!!!** Members mentioned that they think of this phrase often and how much solace it brings.



We also talked about using Medical Alert Wallet cards, and their importance in an emergency. One of us has a wrist bracelet with her information in it. She never leaves the house without it...Hers is from: [RoadID Medical Bracelets](#)

Here is the latest Medical Alert Wallet card from the FSHD Society: [FSHD Society Medic Alert Card 2024](#). Having this additional document in your wallet, with important information specific to our emergency needs, is worth your read/consideration: [Special Considerations for FSHD Patients](#)

Breathe with MD Inc, a non-profit organization with the goal of promoting awareness of the respiratory needs/concerns for (some) individuals with neuromuscular diseases, also has a great Medical Alert Wallet card <https://breathewithmd.org/respiratoryinfocard.html> .

For inside your home you can direct Emergency Management personnel to a document that provides your wishes for medical care outside of the hospital: <https://polst.org/> explains this process more fully. The link below takes you to the form, which is not valid unless signed by your provider:

[Physician Orders for Life Sustaining Treatment outside of the hospital setting. form](#)

This form is named differently in different states (i.e. MOLST), however it is talking about the same basic premise, which are your wishes in different emergency situations, so that Emergency Medical Personnel will know what your specific wishes are.

When talking about fatigue, we touched on the subject of CPAP versus BiPAP. For those of us with affected respiratory muscles (intercostal, accessory, diaphragm) we become hypoventilators, due to the weakened state of these muscles (and maybe more). Having excess CO<sub>2</sub> can cause increased fatigue. We hold on to carbon dioxide (CO<sub>2</sub>) which can build up and become very dangerous. A BiPAP encourages our lungs to push out the CO<sub>2</sub> when we exhale. Having excess CO<sub>2</sub> can cause increased fatigue. *This is a very simplistic description of a complicated process.*

Many well intentioned Pulmonologists are *unaware of the specific needs of individuals with affected respiratory muscles by their neuromuscular disease*. If we are prescribed a CPAP when we really need a BiPAP we are not expelling the CO<sub>2</sub> as we need. For most of us, it is extremely hard to exhale against the continuous positive pressure, we aren't exhaling effectively and hold on to the CO<sub>2</sub>, which at high levels can be extremely detrimental to us. Another positive effect of the BiPAP is that it allows our respiratory muscles to rest, as it essentially is breathing for us (or with very little effort on our part). A CPAP doesn't allow for this important resting need. Please remember we are not all affected by our respiratory muscles. If you are concerned about this, PLEASE talk with your FSHD provider about this.

Here is an article to take to your provider with your concerns: [Respiratory Care of Patients with Neuromuscular Disease](#)

***Additional information:***

Here is a YouTube of Andrea Klein from Breathe with MD, presenting at a FSHD Society University in February of 2024 on Respiratory Concerns in Neuromuscular diseases. [Andrea Klein of Breathe with MD at a FSHD Society University](#)

The *Breathe with MD* website has great information about respiratory concerns that affect some of our fellow FSHDers. <https://breathewithmd.org/index.html> It also has great information on why

those of us affected with respiratory muscles need to be extremely cautious when it comes to oxygen therapy. They also have a terrific support group that is and has been of great help and support to many of us on FaceBook

<https://www.facebook.com/groups/BreathewithMDSupportGroup>

If you'd like professional literature/research articles on respiratory concerns for some individuals with FSHD or neuromuscular diseases. Please let me know, I have a great collection, and would be happy to share. Not all FSHDers have affected respiratory muscles (it isn't our lungs that are affected...it is the muscles that help the lungs work effectively that in some, become affected)...