

## **FSHD Wellness Meeting Notes: Monday, February 13, 2023**

**June Kinoshita** welcomed everyone to our monthly Zoom meeting. It was great to see new faces including some people who live outside of the North American continent! With the aid of online platforms (and over many time zones), we are becoming an international group!

**Ranae Beeker** introduced our two guests—**Kylee Helmke** and **Andrea Morales**—and our meeting topic: **Toward Hope**. Kylee and Andrea are mental health and crisis counsellors who are on staff with **Crisis Text Line\***. This is an organization that began ten years ago and offers “free, 24/7, high quality text-based mental health support and crisis intervention by empowering a community of trained volunteers to support people in their moments of need” (excerpted from their website).

[\* See attached file that lists contact information for **Crisis Text Line** and describes its history, goals and activities. The file also contains several websites of other organizations that provide information and resources related to mental health concerns and wellness.]

**Spoiler Alert:** Kaylee’s and Andrea’s presentation and interactions with us were terrific! Hopefully this can be conveyed in these notes!

Both women began by giving us a short preview of the **Crisis Text Line** and their training/interest in being crisis counsellors. Andrea is bilingual (English/Spanish) & has a degree in science and a Masters degree in psychology & forensics. Kylee obtained a Master’s level degree in psychology/criminology.

Recognizing that living with a diagnosis of FSHD often includes emotional and mental stresses, Kylee and Andrea shared a powerpoint presentation listing aspects of living with a long term chronic condition. FSHD is not well known (even in medical circles) and its progression is variable between individuals.

In random order, here are some of the points they shared:

- Chronic stress can affect our moods, cognition, opportunities, perspective/outlook
- Having an incurable disease is lonely and often isolating. Even family members and/or long term friends may be uninterested in understanding our experiences, concerns, fears
- “Painsomnia”. There are now actual studies which confirm that living with longer term pain and limitations causes more emotional stress in our bodies
- FSHD often interferes with schooling, post secondary choices, work, goals, hobbies and/or relationships
- Initially, FSHD is usually an invisible illness and people see us as looking just fine/well even as we are becoming more aware of how this condition limits us in various ways
- When symptoms become more visible, others often view us through a lense of discomfort/don’t know what to say (**or not say**). Our culture is still uncomfortable dialoguing with people who have some form of disability.

- Having FSHD doesn't shield us from other challenges in life including co-existing health challenges (physical or mental) or other circumstances which cause extra anxiety and stress.
- Stigma and shame (particularly around mental health) is very much a "thing" that often makes it harder to seek help.
- "This is getting too much to live with" "I just want the pain to end" "I can't live like this anymore" "What is the point of living when FSHD has no cure & keeps taking away my ability to enjoy life independently?"
- This can lead to a heightened risk of suicide for those who live with a chronic/longterm condition.

Is there hope? How can someone find help? Kylee & Andrea offered several suggestions.

- We can seek counselling. Finding someone who "gets it" (ie understands the stresses of actually living with a chronic diagnosis) can be challenging depending on our location. Some counsellors are now offering an online option. However, we already have additional expenses (that are part of living with FSHD) and not all of us have insurance coverage. The cost of counselling may not be affordable. And there may be a long waitlist . . .
- Andrea and Kylee shared how getting in touch with the Crisis Text Line can be a good support to contact especially when anyone is feeling really low/discouraged and wants/needs immediate help.
- The Crisis Text Line is a texting service which is available 24/7. The volunteers are trained to be empathetic listeners and supportive helpers. If a specific situation is especially serious, there are back up registered counsellors (with Master's level of education specializing in psychology) who are available too. Sometimes, the volunteer or counsellor will contact emergency responders when someone's needs indicate that is an appropriate response.
- This is a free service and can be accessed when/as needed. People are welcome to contact Crisis Text Line more than once.
- The services of the Crisis Text Line have been instrumental in helping many people feel supported because a volunteer, through texting, offered empathy and validated the person's stress/anxiety without shaming or dismissing their situation.

What if someone we know is feeling suicidal and confides in you? How can we respond?

- Listen and ask direct questions ie How are you? How can I support you?
- Affirm your care and support for the person . . . that the person matters / is of value. Even if they deny those words as being valid, the person has heard words that may help the person to continue sharing or recall the words later.
- If you sense the person may be suicidal, be direct and ask if the person: Are you feeling suicidal? Do you have a plan? Have you access to whatever means you plan to use? What is your time frame for your plan—immediate? Later? If things don't improve?
- A person may be relieved to have someone ask these questions and will be open to you contacting a mobile crisis line or phoning non emergency police # (or 911 line) for an in person evaluation and help. (Communicate that it is a psychiatric emergency / person is suicidal).

- However, being asked these questions may further agitate a person ie increase the person's anger and stress. If possible, continue to dialogue with the person. If they hang up or leave, call a crisis line to share your concerns. The crisis line volunteer won't be able to connect with the person (who is in crisis) but can offer you support and suggestions.
- Conversations with someone who is in the midst of a mental health crisis &/or suicidal are draining—take care of yourself by debriefing with a friend or family member or by contacting a Crisis Text Line (or a similar organization). If possible find some time to do something relaxing for yourself during what can be a very stressful time.

Are there other ways we can discover support in our day to day journey of having FSHD?

- Indeed yes, said Andrea and Kylee. Identifying the stressors (“naming them”) is a step forward (versus “stuffing” or denying negative emotions)
- They suggested identifying our support system (or our potential support system)
- Think of friends or family members, co-workers or neighbours who may already be helping us by providing practical or emotional support
- Accept that no one person is likely able to be our total support system. Maybe we have a friend (local or at a distance) or family member that we can ask to be a safe person we can share openly with knowing what we share will be kept confidential. Someone else may be willing to take us to appointments or help with practical things (ie shopping, cleaning, yard work, etc)
- Learning about FSHD and staying abreast of new FSHD information and research can be encouraging.
- Joining FSHD groups help us realize we are not alone. Members often share “What can I do to address a specific problem” and various & useful suggestions are offered.
- Online and Zoom groups are a great way to learn of helpful resources related to FSHD.
- As FSHD limitations increase, look for ways to adapt and/or find another activity or hobby to substitute for what is no longer feasible. Someone mentioned being part of a book club (which could be in person or online). Over time, the book discussion time shortened as the members grew in sharing updates/joys/challenges/support/camaraderie.
- Finding a volunteer opportunity can provide a sense of value and worth. Be a mentor or look for someone who wants a friend or be an advocate to raise awareness of FSHD or to offer constructive ideas to increase accessibility in our communities . . .

One of our Wellness group members volunteers with the Crisis Text Line. Some group members asked her (and Kylee and Andrea) what was involved in becoming a volunteer. Look up the Crisis Text Line website. There is lots of information to read, including frequent questions and answers. An application form is also on their website. A 30 hour training course is required along with a willingness to commit to volunteer 4 hours per week (until one has volunteered at least 200 hours). Many volunteers continue beyond the 200 hours.

This particular volunteer opportunity may or may not interest all our group members. But by learning more about the organization, we can share the information with someone else who

might be interested in being a volunteer. Knowing of the existence of this service is definitely a plus—especially to recommend it to someone who would benefit from the support this group offers on a 24/7 basis.

Group members expressed much appreciation for Andrea's & Kylee's presentation. Their non-judgemental acceptance of the realities of having FSHD, of grieving the changes and stresses which FSHD brings was refreshing and hopeful. Thank you so much for your affirmation of our challenges and for the empathy & encouragement which you shared with us!

*{One Wellness Group member mentioned an article he'd recently read and shared the article title and author's name. Here it is (you will need to do a Google search to find it): Article title: The Link Between Stress Disorders and Autonomic Dysfunction in Muscular Dystrophy. Author's name: Rasna Sabharwal}*

**Our next Wellness Group meeting will be a "Movie Night" on Monday, March 13, 2023  
at 2pm PT, 3pm MT, 4 pm CT, 5 pm ET.**

[NOTE: Some states/provinces will be springing ahead (aka time change) on Sunday 12th. Do an online check ahead of time in case meeting time in your location is affected.]

Check your mailbox for an email from June Kinoshita with the link to the movie:

**I Didn't See You**

*We will be discussing **I Didn't See You** in break out rooms during our usual meeting time.  
Viewing the movie ahead of time is therefore recommended. Thanks!*

A reminder that Rick will be online half an hour before our Wellness Meeting begins to host a time of visiting between us. It's also a good time to ask questions or share suggestions. All are welcome to enter the pre-meeting time at 1:30 pm. Hope to see you then!

