LIVING WELL WITH FSHD

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GOALS OF SESSION

• To share
• To raise awareness
• To learn
• What does life with FSHD mean to you? What are the main struggles and challenges you are facing?
• How do you deal with these challenges? What has worked well? What has worked less well?
STRUGGLES AND CHALLENGES MAY INCLUDE

- Increased limitations
- Decreased mobility
- Pain and/or fatigue
- Some activities are harder or even impossible
- Need for assistance
- Worries about the future
- Relationships with others (partners, family member, friends, colleagues, others)
- Social contact and social support
- Employment issues
- Economic issues
SERENITY PRAYER

GRANT ME
THE SERENITY
TO ACCEPT THE THINGS
I CANNOT CHANGE,
THE COURAGE TO CHANGE
THE THINGS I CAN, AND
THE WISDOM TO KNOW
THE DIFFERENCE.

-NIEBUHR-
• What should we accept?
• What should we not accept?
• How can we know the difference?
Struggles and challenges arise from multiple sources

• Bodily struggles (FSHD)
• Physical and environmental barriers
• Attitudinal barriers
• Internal barriers
THINGS WE SHOULD ACCEPT

• The diagnosis of FSHD and its mode of transmission
• the progressive nature of the disease
• Inevitable losses and associated feelings
• the fact that certain activities are no longer possible or too burdensome to make them worthwhile
THINGS WE SHOULD CHALLENGE

• Discrimination
• Stereotypes
• Lack of respect
• Harmful messages about yourself, your life, or what you can or cannot do
• Barriers to physical access that can be removed
• Practices that limit or prevent participation
• Internal oppression
Disability: Individual/Medical Model

- Impairment is the problem
- Impairment = restricted life
- Impairment as tragedy
- Focus on cure
- Lack of control
- Professionals in charge
Disability: Social/Minority Model

- Lack of access is the problem
- Disability = societal barriers that restrict lives
- Disabling environments as tragedy
- Focus on removing barriers
- Self determination
- PWD in charge of their lives
- Nothing about us without us
DISABILITY IS AN INTERACTION

• Neither purely medical nor purely social
• An interaction between
  • Health condition
  • Personal factors
  • Environmental factors
• These factors can impede or facilitate functioning
• Many barriers are socially created and thus removable
WE HAVE COME A LONG WAY…

- The disability rights movement
- The Independent living movement
- Disability rights legislation (ADA)
- Positive perceptions, messages & role models
- Disability Studies
- Disability community and culture
We have come a long way…

• According to the UN Convention on the Rights of Persons with Disabilities:

• “...disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others”
BUT HAVE A LONG WAY TO GO

- Systemic Barriers
  - High rates of poverty
  - Unemployment and underemployment
  - Affordability of assistive devices
  - Personal Assistance Services
- Social/interpersonal barriers
  - Ableism
  - Spread effect
  - Interaction strain
- Internal/intrapersonal barriers
  - Learned helplessness
  - Internalized oppression
  - Avoidance and isolation
Happiness and Well-being

- Good Relationships
- Life satisfaction and our evaluation of important life domains
  - Work
  - Health
  - Family
- Positive emotions such as joy, optimism, engagement
- Learning, growth, accomplishment
- Meaning and purpose
- Self-efficacy and self-determination
Health, Context and Skills

• Many factors within the person and his or her environment mediate the relationship between impairment and life satisfaction
• Life satisfaction is strongly related to our perceived ability to have satisfying relationships, carry out valued roles and engage in desired activities
• Removing barriers to meaningful engagement and participation can enhance well-being
• In addition, people can learn and practice specific skills that can help them overcome challenges and reach desired goals
Wellness: I COPPE Domains of life

- Interpersonal well-being
- Community well-being
- Occupational well-being
- Physical well-being
- Psychological well-being
- Economic well-being
BET I CAN: Seven scientific principles to promote well-being
BET I CAN STRATEGIES

Well-Being

- Behaviors
- Emotions
- Thoughts
- Interactions
- Context
- Awareness
- Next Steps

SET A GOAL
CREATE POSITIVE HABITS
BET I CAN

Well-Being

- Behaviors
- Emotions
- Thoughts
- Context
- Interpersonal
- Awareness
- Next Steps

MANAGE NEGATIVE EMOTIONS
COLLECT POSITIVE EMOTIONS
BET I CAN

Well-Being

Behaviors

Emotions

Thoughts

Interactions

Context

Awareness

Next Steps

CHALLENGE ASSUMPTIONS WRITE A NEW STORY
BET I CAN

Well-Being

Behaviors

Emotions

Thoughts

Interactions

Context

Awareness

Next Steps

CONNECT

COMMUNICATE
BET I CAN

READ THE CUES
CHANGE THE CUES

Well-Being

Behaviors

Emotions

Thoughts

Interactions

Context

Awareness

Next Steps
KNOW YOURSELF
KNOW THE ISSUE

Well-Being

Behaviors

Emotions

Thoughts

Context

Interactions

Next Steps

Awareness
BET I CAN

MAKE A PLAN
MAKE IT STICK

Well-Being

Behaviors

Emotions

Thoughts

Context

Interactions

Awareness

Next Steps
How can you use BET I CAN?

• What skills can you use in your situation?
• Select one and apply it to your life.
• Share with the person next to you.
• Consider sharing with the rest of the group.
TAKE-HOME MESSAGE

• Accept yourself and practice self-compassions
• Identify and utilize your strengths
• Commit to your goals and work to attain them
• Form strong social bonds
• Communicate your needs
• Know your rights and be a good self-advocate
• Feel valued and add value
• Join with others to fight ableism, oppression and discrimination