

LIVING WELL WITH FSHD

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GOALS OF SESSION

- To share
- To raise awareness
- To learn

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- 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-

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- 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



BET I CAN: Seven scientific principles to promote well-being



BET I CAN STRATEGIES



BET I CAN



MANAGE NEGATIVE
EMOTIONS
COLLECT POSITIVE
EMOTIONS

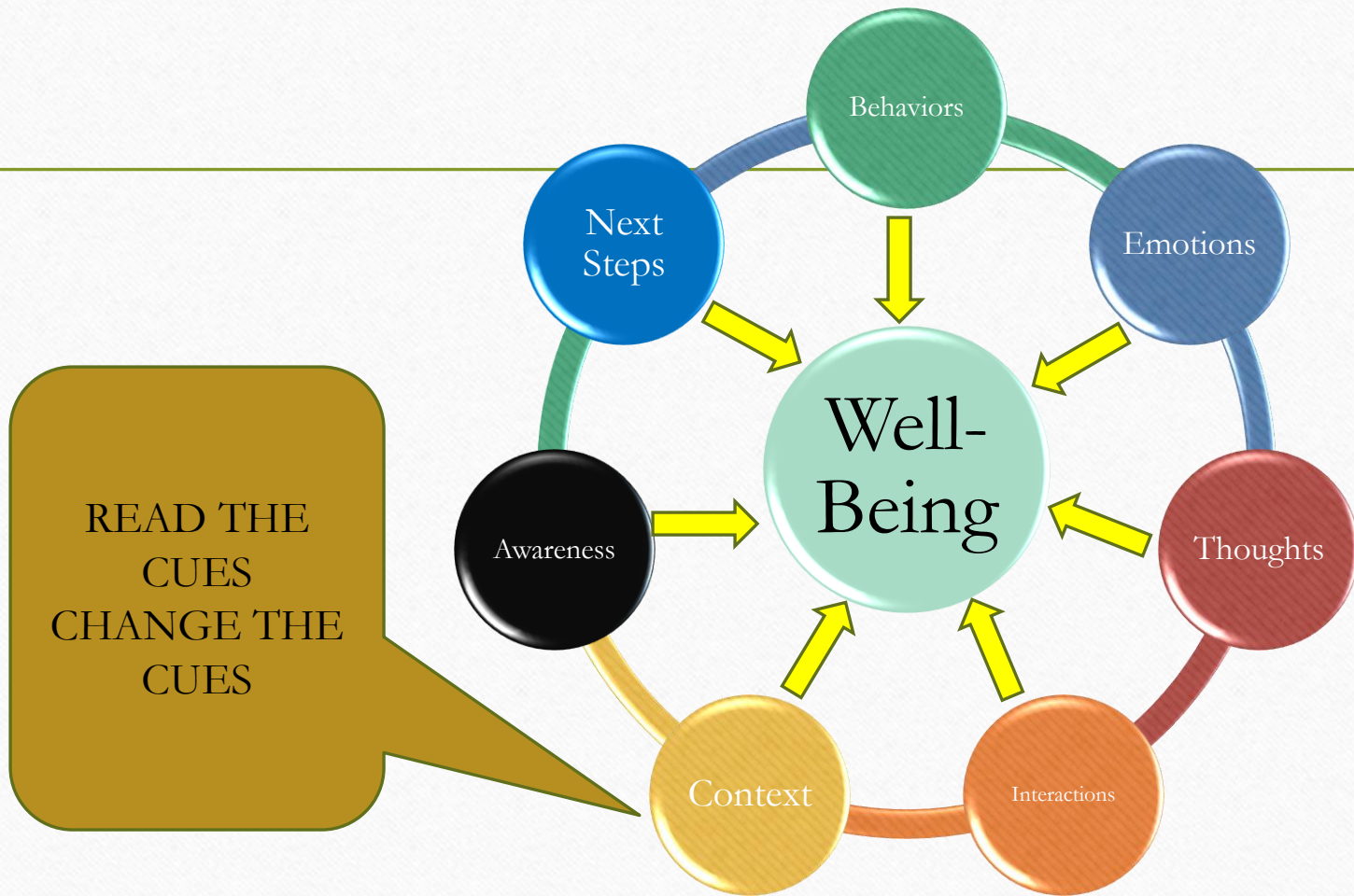
BET I CAN



BET I CAN



BET I CAN



BET I CAN

KNOW
YOURSELF
KNOW THE
ISSUE



BET I CAN

MAKE A PLAN
MAKE IT
STICK



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