Loving well

Living with a person with FSHD
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Well-Being

Experiences of pleasure and purpose, over time, in “i coppe” domains of life
Domains of Well-Being

- **INTEPERSONAL**
- **COMMUNITY**
- **OCCUPATIONAL**
- **PHYSICAL**
- **PSYCHOLOGICAL**
- **ECONOMIC**
Well-Being

PLEASURE
• Joy
• Humor

PURPOSE
• Mattering
  – feeling valued
  – adding value
Mattering
Feeling Valued + Adding Value → Mattering
Threats to Feeling Valued

Invisible

Entitled

Feeling Valued

Adding Value

Mattering
Threats to Adding Value

Feeling Valued

Mattering

- Helpless
- Autocrat

Adding Value
Mattering in Loving Well

• How do you experience mattering in living with a person with FSH?
• How do you feel valued?
• How do you add value?
Challenges in Loving Well

• What challenges do you experience in living with a person with FSH?
• What prevents you from feeling valued?
• What prevents you from feeling that you are adding value?
Reciprocity

• Reciprocity is important in all relationships
• Rigid roles as caregiver or care receiver can lead to stigma and stereotypes
• Both parties entitled to express and fulfill basic human needs
Dignity

• Dignity is one of the highest human values
• Pity does not foster dignity
• We gain dignity not just by feeling valued, but also by opportunities to add value
• Person with FSH, like the rest of us, is seeking to add value, not just to be in “recipient” role
Creativity

• There is only one family in the world with the particular context of your life.
• You know your family situation best.
• Embracing rigid social norms of what it means to be happy can limit your fulfillment in life
• How can you turn this situation into a unique opportunity for you to make meaning in life?
Competency

• Understanding a situation is important, but knowing how to deal with it is even more useful

• We need to develop and share skills related to the experience of “mattering”

• What skills can we learn to “love well” when we live with a person with FSH?
Competency = Skills in drivers of change

- BEHAVIORS
- EMOTIONS
- THOUGHTS
- INTERACTIONS
- CONTEXT
- AWARENESS
- NEXT STEPS
Domains of Well-Being

- INTEPERSONAL
- COMMUNITY
- OCCUPATIONAL
- PHYSICAL
- PSYCHOLOGICAL
- ECONOMIC
BET I CAN: Seven scientific principles to promote well-being
BET I CAN STRATEGIES

SET A GOAL
CREATE POSITIVE HABITS

Well-Being

Behaviors
Next Steps
Emotions
Thoughts
Awareness
Context
Interactions
BET I CAN

Well-Being

Behaviors

Emotions

Thoughts

Interpersonal

Context

Awareness

Next Steps

COPE WITH 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

READ THE CUES
CHANGE THE CUES

Well-Being

Behaviors

Next Steps

Awareness

Context

Emotions

Thoughts

Interactions
BET I CAN

KNOW YOURSELF
KNOW THE ISSUE

Well-Being

Behaviors

Emotions

Thoughts

Interactions

Context

Awareness

Next Steps
BET I CAN

MAKE A PLAN
MAKE IT STICK

Well-Being

Behaviors

Emotions

Thoughts

Interactions

Context

Awareness

Next Steps
## Fun For Wellness

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Mini-Games Teach Wellness
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.