Questions

• What is a healthy relationship?
• What does it look like?
Healthy relationship: Affection

- Spending quality time together
- Caring for one another
- Empathizing and feeling understood
- Expressing appreciation and affection
- Celebrating each other’s strengths and accomplishments
Healthy relationship: Communication

- Expressing needs and wishes
- Shared decision making – voice and choice
- Managing stress and crisis
- Resolving conflict
- Good balance between separateness and togetherness
Question

• What does it take to make a relationship healthy?
Happy relationships require

• Making time for the relationship
• Finding ways of having fun together
• Showing affection and providing support (5-1 ratio)
• Ensuring that everyone’s needs are met
• Sharing how you feel and expressing your needs
• Being a good listener
• Being willing to deal with differences
• Expressing concerns and grievances in a constructive manner
Your Turn

• All families have challenges. Based on your experience, what are some challenges for families with FSHD?

• How do you foster healthy relationships in families with FSHD?
Challenges in families with FSHD

• Impact of disease progression on individuals with FSHD
• Implications for other family members
• Managing negative emotions
• Balancing needs and resources
• Confronting barriers in the physical and social environment
• Confronting internal barriers
• How do you foster healthy relationships in families with FSHD?
Foster healthy relationships

• Cope with FSHD as a family unit
• Acknowledge FSHD but not be defined by it
• Adapt to the progression of the disease
• Address issues of interdependence and need for assistance
• Affirm the importance of meeting everyone’s needs
• Attend to reciprocity and mutual care
Gifts you can give and receive

• Gifts of the hand
• Gifts of the heart
• Gifts of the head
Foster healthy relationships

- Communicate openly and honestly
- Acknowledge difficulties, challenges and losses
- Build resilience and find meaning
- Create a narrative of family strengths
- Cultivate common interests and shared activities
- Seek resources and extending the circle of care
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
Domains of Well-Being

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

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

Well Being

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BET I CAN STRATEGIES

SET A GOAL
CREATE POSITIVE HABITS

Well-Being

Behaviors

Next Steps

Emotions

Awareness

Thoughts

Context

Interactions
BET I CAN

Well-Being

- Behaviors
- Emotions
- Thoughts
- Interpersonal
- Context
- 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

Well-Being

Behaviors

Next Steps

Emotions

Awareness

Thoughts

Context

Interactions

READ THE CUES
CHANGE THE CUES
BET I CAN

KNOW YOURSELF
KNOW THE ISSUE

Well-Being

Behaviors
Emotions
Thoughts
Interactions
Context
Awareness
Next Steps
Videos

Interpersonal

Physical

Psychological

Economic

Occupational

Community

Psychological

Physical

Interpersonal
Mini-Games Teach Wellness
Interactions: Connect and Communicate

• Meaningful relationships and social support are critical to our health and happiness.
  – Make time and share your inner life
  – Express appreciation and affection (the 5 to 1 ratio)
  – Manage Conflict
  – Focus on strengths
  – Take delight in loved ones’ successes
Communicate with L.O.V.E.

- Listening
- Observing
- Verbalizing
- Empathizing
Listen Well

• Give the gift of listening
• Demonstrate your intent to listen
• Remove barriers to listening
• Use following skills
• Confirm your understanding
Observe Well

- Facial expressions
- Body language
- Tone of voice
- Read between the lines
- Congruency between verbal and nonverbal communication
Verbalize Well

• Be assertive
• Say what you mean
• Avoid double messages
• Make your message clear
• Own your message
Empathize Well

• Place yourself in the other person’s shoes
• See things from their perspective
• Feel what they are feeling
• Demonstrate empathy
How can you use BET I CAN?

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