Promoting Mental Wellness In Teens and Adults with Down Syndrome

Down Syndrome Association of Greater St Louis: A Healthy Future: The Physical and Mental Wellbeing of Adults with Down Syndrome

August 5, 2017 | Brian Chicoine, MD
Adult Down Syndrome Center
What is Mental Health Promotion?
What is Health Promotion?

• Living longer and healthier lives is an active process.
• Adolescents and adults with Down syndrome can and should be encouraged to participate in their own health promotion.
The Interaction Between Physical and Mental Health

- Promoting one promotes the other
- Any and all behavioral change should be viewed as a possible communication tool
Self-Promotion

People who can participate in their own health promotion have a significant increased likelihood of being healthy.

-NIH, Health Literacy
• Relationships/Friends
• Family
• Healthy eating
• Being active
• Employment
• Volunteering

• “I am happy with who I am”
• “I love myself”
Our Approach to Health

- Why are you addressing that?
- Medical
- Psychosocial
- OT
- Advocates
- Nutrition
- Zumba, social skills, garden club, AD support, Grief support group, fitness run/walk, conference
Leo Foley
1907-1947
Life Expectancy

• Life expectancy:
  • 1907: 9 years
  • 1984: 28 years
  • Today: 60 years

• One of oldest well-documented person with Down syndrome, 83 years old at death
“Two Syndromes”

- Expectations
- Life Expectancy
- Opportunities
  - Goals
| All is not Down syndrome | There are common characteristics of people with Down syndrome |
Self talk and Imaginary friends

• Developmental Stage-Appropriate Behavior
• Coping strategy/defense mechanism
• Boredom
• Change in quality or quantity may be a sign of stress or mental illness
The Groove

• Tendency towards sameness, repetition
• Functional
• When does it become problematic?
Unique Memory Skills

- Excellent for remembering visual data (photographic-like)
- Limited sense of chronological order
- Memories re-experienced as if happening now
What is Your Experience?
Grief

• Death
• Life changes
• Family changes
• Delayed response
The Interaction Between Physical and Mental Illness

- Sleep apnea
- Hypothyroidism
- Gout
Alzheimer disease
What is the Association between Down syndrome and Alzheimer Disease?

• Nearly all people with Down syndrome have plaques and tangles by age 40.

• All people with DS over age 60

Neuropathological Changes of Alzheimer’s Disease in a Person with Down’s syndrome
DMA Mann
In The Neuropathology of Dementia
MM Esiri and JH Morris
University Press: Cambridge
1997
Alzheimer’s dementia: Key diagnostic issues

- Memory deterioration
- Loss of previously mastered skills
- Incontinence
- Gait apraxia
- Dysphagia (swallowing problems)
- Seizures (77% vs 2%)
- Weight loss
- Withdrawal, apathy and/or other psychological or personality changes
In our practice

- Average age of onset – 52.3 years
- Average age of death – 55.9 years
- Average from onset to death – 3.6 years (compare to approximately 5.9 years)
Treatment

- Cholinesterase inhibitor (donepezil/Aricept, galantamine/Razadyne, etc.)

- Memantine (Namenda)
21 y/o man with rapid onset of skill loss

- Diagnosed with Alzheimer disease
- Medical
- Psychological
- Social
- Regression
Prevention and Treatment

- Medications
- Non-medicinal
Nutrition

• Obesity
  – Secondary disabilities
• Food as medicine
• Participate in food preparation
• Recommendation
  – Portion control
  – Limit carbohydrates, attention to protein intake
  – Variety of colors
Activity/Exercise

• Weight management
• Improved sleep
• Sense of wellness
• Disease prevention
• Exercise as medicine
People with Down syndrome as teachers and peer supporters

- Peer support
- Conference
- Videos
Social skills

• Volunteer opportunities

• Social skills groups
Family, Friends, Inclusion

- Connecting
- Staying connected
- Inclusion
- The right to integrate and the right to congregate
Calm time

• Chicago Botanic garden
Jane and Sensory/Anxiety

- Other ways to provide support, anxiety-reduction
- Video
- Feedback?
Everything is heath,
health is everything
Support in your community

- Resources
  - Videos of people with DS
  - 20 things I want my Health Care Provider to Know
  - Written pieces
  - Facebook
- What is being done in your home, your community?
- What do you need?
Resources

• Web page: https://www.advocatehealth.com/luth/health-services/adult-down-syndrome-center/

• Facebook: https://www.facebook.com/adultdownsyndromecenter/