Clinic: 650-725-5792
Support group: Andrea Kwan, MS, LGC andreak@stanford.edu

Co-Directors
Veronica Santini, MD, MA
Sharon Sha, MD, MS

Neuropsychiatrist
Sepideh Bajestan, MD, PhD

Genetic counselor
Carly Siskind, MS, LCGC

Nurse Coordinator
Victoria Tanoury, RN, CNRN

Social worker
Amee Jaiswal, MSW

Movement Disorder Neurologists
Laurice Yang, MD, MHA
Hok Morita, MD, MS
NUTRITION IN HUNTINGTONS DISEASE
Food Intake

- Involuntary movements
- Lack of voluntary control of movements
- Chewing & swallowing problems
- Depression or Anxiety
- Medication
- Cognitive Issues
- Involuntary movements
- Behavioral Issues
Treatment

- Higher total energy requirement
- Ratio of fat and carbohydrate despite sugar cravings
- Increased animal protein requirement
- 30-35ml fluid intake/kg
<table>
<thead>
<tr>
<th>Color</th>
<th>Phytonutrient</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red</td>
<td>Lycopene</td>
<td>DNA &amp; the urinary tract</td>
</tr>
<tr>
<td>Purple</td>
<td>Resveratrol Flavanoids</td>
<td>Heart, brain, bone, arteries, cognition</td>
</tr>
<tr>
<td>Green</td>
<td>Lutein, isoflavanoids</td>
<td>Eye, blood vessel, cells, liver, and lung. Helps heals wounds</td>
</tr>
<tr>
<td>White</td>
<td>Allyl sulphides</td>
<td>Fights cancer</td>
</tr>
<tr>
<td>Yellow</td>
<td>Alpha &amp; Beta Carotene, leutin</td>
<td>Immune function, growth and development</td>
</tr>
</tbody>
</table>
Mid-Stage Diet

- Moist and soft foods
- Food should be steamed before blending to prevent loss of nutrients
- Upright position
- Swallowing precautions
HDSA Northern CA Convention 2016
Importance of Exercise/PT/OT and Huntington’s disease

Laurice Yang, MD MHA
May 20, 2016
Agenda

1. Science Behind Exercise
2. Fall Prevention Education
3. Caretakers and Therapy

Huntington Disease Society of America 2016
The Science Behind Exercise

It's more than just exercising
The Science Behind Exercise

- Exercise is **NOT just for strength and balance**
  - Studies have shown that with exercise can:
    - Increase **nerve growth factors**
    - Increased **blood flow** to the brain
      - Delivery these growth factors
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can:
    • Increase **nerve growth factors**
    • Increased **blood flow** to the brain
      – Delivery these growth factors

• **NEUROPROTECTIVE**
  – Protects the brain from insult
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can:
    • Increase **nerve growth factors**
    • Increased **blood flow** to the brain
      – Delivery these growth factors

• **NEUROPROTECTIVE**
  – Protects the brain from insult
The Science Behind Exercise

- Exercise is **NOT just for strength and balance**
  - Studies have shown that exercise can:
    - Increase **nerve growth factors**
    - Increased **blood flow** to the brain
      - Delivery these growth factors

- **NEUROPROTECTIVE**
  - Protects the brain from insult
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can:
    – **IMPROVE Pain**
      • Non specific lower back pain
        – Exercise group – **experienced less pain**
        – Neuroimaging supports pain center less activated
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – *Studies* have shown that with exercise can:
  – **IMPROVE Pain**
    • Non specific lower back pain
      – Exercise group – *experienced less pain*
      – Neuroimaging supports pain center less activated
    – People who exercise - **greater tolerance** for pain
The Science Behind Exercise

- Exercise is **NOT just for strength and balance**
  - Studies have shown that with exercise can:

  - ** IMPROVE Pain**
    - Non specific lower back pain
      - Exercise group – **experienced less pain**
      - Neuroimaging supports pain center less activated

    - People who exercise - **greater tolerance** for pain

PAIN + ↑ TOLERANCE =
The Science Behind Exercise

- Exercise is **NOT just for strength and balance**
  - Studies have shown that with exercise can:
    - **IMPROVE Pain**
      - Non specific lower back pain
        - Exercise group – **experienced less pain**
        - Neuroimaging supports pain center less activated
      - People who exercise - **greater tolerance** for pain

\[
\text{PAIN} + \uparrow \text{TOLERANCE} = \downarrow \text{SUFFERING}
\]
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can:
  
  – **IMPROVE** Depression
    • **PGC-1alpha** is produced in exercise
    • **ANY exercise** shows an improvement
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can
  – **IMPROVE immune systems**
    • Natural anti-inflammatory proteins are increased
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can
  – **IMPROVE immune systems**
    • Natural anti-inflammatory proteins are increased
  – Shown to **increase NK cells** (Natural Killer)
    • To monitor “bad” cells
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can

  – **IMPROVE immune systems**
    • Natural anti-inflammatory proteins are increased
  – Shown to **increase NK cells** (Natural Killer)
    • To monitor "bad" cells
    • maybe decrease chance of cancer
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – Studies have shown that with exercise can
    • patients who used **treadmill:**
      • Greater manual dexterity
    • Neuroimaging showed **increased activity**
      – In the motor cortex in both arms and legs
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
• Cognition improves
  – Decision making
  – Memory
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**

• **Cognition improves**
  – Decision making
  – Memory

- More Blood and Growth Factors in Brain
- Less Depressed
- Less Pain
- Less Sick
- Cognition
Exercise is **NOT just for strength and balance**

- PROTECTS nerves
- Improve PAIN
- Improve DEPRESSION
The Science Behind Exercise

• Exercise is **NOT just for strength and balance**
  – PROTECTS nerves
  – Improve PAIN
  – Improve DEPRESSION
  – Improves IMMUNE SYSTEM
  – Improves DEXERITY/MOVEMENTS in all four limbs
    • Not just the limbs exercised
  – Improves COGNITION
Agenda

1. Science Behind Exercise
2. Fall Prevention Education
3. Caretakers and Therapy

Huntington Disease Society of America 2016
Fall Prevention

Risk Factors for Falling and What To Do About It
Presentation Goals

1) Recognize the RISK FACTORS for falls

2) Describe how physical and occupational therapist can help you reduce falls
The Facts

- 1/3 of seniors over 65 and over fall each year

- In 2015, 2.8 million nonfatal falls among older adults were treated in ER

- In 2015, $30 billion spent on medical costs
Fall Prevention

• Even if you are **not injured** from your fall – will develop:

  • **THE FEAR OF FALLING**

---

**Fear of Falling**

- Moving Slower
- Avoid movement
- Deconditioned
- Loss of Strength

**Increased Fall Risk**
Fall Prevention

• Even if you are not injured from your fall – will develop:

  • THE FEAR OF FALLING

Fear of Falling
  Moving Slower
  Avoid movement
  De conditioned
  Loss of Strength

Increased Fall Risk
Fall Prevention

• Even if you are **not injured** from your fall – will develop:

HOW DO WE STOP \( \Rightarrow \) **THE FEAR OF FALLING**

**Fear of Falling**
- Moving Slower
- Avoid movement
- De conditioned
- Loss of Strength

**Increased Fall Risk**
Fall Prevention

Why do Falls Happen?
Fall Prevention

Why do Falls Happen?

• Physical risk factors
  – Changes in your body that increase your risk for a fall
Fall Prevention

Why do Falls Happen?

• **Physical risk factors**
  – Changes in your body that increase your risk for a fall

• **Behavioral risk factors**
  – Things we do or don’t do that increase our fall risk
Fall Prevention

Why do Falls Happen?

• Physical risk factors
  – Changes in your body that increase your risk for a fall

• Behavioral risk factors
  – Things we do or don’t do that increase our fall risk

• Environmental risk factors
  – Hazards in our home or community
Fall Prevention

Take a look at this scene:

• What are environmental risk factors?

Photograph courtesy of the UIC Dept. of Occupational Therapy
Fall Prevention

Take a look at this scene:

• What are **environmental risk factors**?

• What are **behavioral risk factors**?
Fall Prevention

Take a look at this scene:

• What are **environmental risk factors**?

• What are **behavioral risk factors**?

• If she has HD, what **physical risk factors**?
Fall Prevention - What will you do to MINIMIZE these risks?

• What will you do to MINIMIZE these risks?
  • Physical risk factors
  • Behavioral risk factors
  • Environmental risk factors
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical risk factors
  – Understanding your body
  – Understanding your NEW limitations/capabilities (PT/OT)
  – Common in HD patients
    • chorea, cognitive, balance and gait issues
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical risk factors
  – Understanding your body
  – Understanding your **NEW limitations**/capabilities (PT/OT)
  – Common in HD patients
    • chorea, cognitive, balance and gait issues
  – Other medical issues
    • Vision, Inner Ear, Sensation Problems
    • Arthritis, Past broken bones, Pain
    • Alcohol Use, Hydration
    • Foot Wear
  – Medications
    • Working with your doctor
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical risk factors

• Behavioral risk factors
  – Things we do/don’t do that increase fall risk
  – Not knowing (ie: OT / PT)
    • Tap into resources available to you
Fall Prevention - What will you do to **MINIMIZE** these risks?

- **Physical therapy (PT)**
  - walking and balance/ strengthening core
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical therapy (PT)
  – walking and balance/ strengthening core
  – Fall prevention
    • Training skills and strength to prevent falls

• Teaching you what you CAN/CANNOT do given your limitations
  – How to fall more safely
  – How to get up from a fallen position
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical therapy (PT)
  – walking and balance/ strengthening core
  – Fall prevention
    • Training skills and strength to prevent falls

• Teaching you what you CAN/CANNOT do given you limitations
  – How to fall more safely
  – How to get up from a fallen position

Fear of falling
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical therapy (PT)
  – walking and balance/ strengthening core
  – Fall prevention
    • Training skills and strength to prevent falls

• Teaching you what you CAN/CANNOT do given you limitations
  – How to fall more safely
  – How to get up from a fallen position
Fall Prevention - What will you do to **MINIMIZE** these risks?

- **Physical therapy (PT)**
- **Occupational therapy (OT)**
  - walking and balance/ strengthening core
  - **EDUCATION**
    - consequences of falling
    - Awareness of your **specific risk factors**
      - Your physical limitations
      - Your environment
Fall Prevention - What will you do to MINIMIZE these risks?

- Physical therapy (PT)
- Occupational therapy (OT)
  - walking and balance/ strengthening core
  - EDUCATION
    - consequences of falling
    - Awareness of your specific risk factors
      - Your physical limitations
      - Your environment
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical risk factors

• Behavioral risk factors
  – Things we do/don’t do that increase fall risk
  – need more education

• Use your resources available to you
  – PT/OT to help you understand you better
Fall Prevention - What will you do to MINIMIZE these risks?

• Physical risk factors
• Behavioral risk factors
• Environmental risk factors
  • Hazards in our home
    • 70% falls in the Home/30% in public areas
      – Poor Lighting (ie nightlights)
      – Clutter on the floor
      – Beds/nightstand proper height
      – Items hard to reach
  • Hazards in the community
    – Cracked sidewalks
    – Lack of hand rails
    – Safe public areas
Conclusions:

• Physical risk factors
  – Changes in your body that increase your risk of falls

• Behavioral risk factors
  – Things we do or don’t do that increase our fall risk

• *Environmental risk factors*
  – Hazards in our home or community

EDUCATE YOURSELF!!
Agenda

1. Science Behind Exercise
2. Fall Prevention Education
3. Caretakers and Therapy

Hope and Cope 2015
Caretakers and Therapy

Caretakers role in Therapy
Caregivers

• The medical team’s Eyes and Ears
Caregivers

• The medical team’s **Eyes and Ears**

• Execute treatment plan as well
  – Therapy plans and instructions
  – Understanding **risk factors**
  – Encouraging and reinforce importance of exercise
Caregivers

• **Working as a Team**
  – Caregivers
  – Physicians
  – Nurses
  – Physical Therapist
  – Occupational Therapist
  – Speech Therapist
  – Social Worker
  – Psychologist
  – Spiritual Counselors
  – Nutritionists
  – Support Groups
  – Senior Center
Conclusion:

• **Exercising**
  – More than just strengthening
  – **Protects your brain and body** on a microscopic level

• **To Prevent Falls**
  – Educating yourself
  – **Know you risk factors**
    • Physical, Behavior, Environmental

• **Caregivers**
  – **Vital part of Therapy Team**
Remember...

Falls **CAN BE** Prevented

Take charge of your **HEALTH**
utilize the **RESOURCES** around you
Thank you!!
American occupational association therapy Inc


Florida Injury Prevention Programs for Seniors (FLIPS)


References


