Living with Huntington’s Disease: A (RE)Introduction to Best Practices

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For our time together!

- Understanding & treatment of Huntington’s Disease is improving
- The question of whether a cure exists has shifted!
  - Maintain standards of living
- Heterogeneity in onset and progression
  - We will try to cover the spectrum
- This workshop will reintroduce:
  - Standard best practices
    - Cognitive, physical, occupational, speech therapy
  - Possibly introduce new suggestions to implement, today!
    - Technology and strategies
Broad Topics:

1. A little research (for context)
2. Assistive Technology
   • Integrating tech into everyday
   • A tour of Durable Medical Equipment (DME)
3. Compensatory Physical Techniques
   • Home Exercises
4. “Hacks” for Activities of Daily Living (ADL)
   • Simplify to accommodate cognitive change
   • Living Positively & Maintaining Optimism!
A little Research!
Ionis and Roche-Genentech HTTRx

- Huntingtin-lowering drug
  - SAFE in lowering levels of Huntingtin protein
    - BUT initial study focused on SAFETY, not EFFICACY
      - GOAL of current Phase 3 clinical trial (underway!)
    - The drug did reach its genetic target
      - BUT < 50 participants, which is too small to be sure
        - Practically promising! just not yet statistical.
- When will this be available??
  - Difficult to say... like many things in life... it depends
  - Lots of steps to take from lab to clinic, but...
  - C-Path for FDA (HD-RSC)
Preliminary Benefits of HTTRx

• Correlation revealed between:
  • Reductions in huntingtin and improvements in clinical measures, specifically:
    • Cognitive processing measure
    • Composite HD symptom scale:
      – 4 domains of clinical performance and capacity in HD:
        » motor function
        » cognitive function
        » behavioral abnormalities
        » functional capacity
• These benefits occurred THREE months after first dose
  – maximum effect projected at SIX months
• Next stages?
  – Shown to be safe
  – Next is large-scale studies to demonstrate efficacy!

BUT UNTIL THEN…
A List of “Assistive Technology” that Caregivers have found Extremely Helpful

1. Shower nozzles (provide hot water at constant temp.)
2. Automatic gas/electricity/stove/water shut-off (infrared)
3. Automatic refrigerator door closer
4. Simple remote control with large and clear buttons
5. Electronic medication reminders
6. Wristband HR and blood pressure monitors
7. Toilet seat with automatic lift assistance
8. Photo button telephone
9. Verbal prompting devices about essential items before leaving

(Mao et al., 2015)
Assistive Technology (ATECH/AT)
What is ATECH or AT?

- **Defined** by the Technology-Related Assistance of Individuals with Disabilities Act of 1998 as...

**Equipment, product system, or program:**
- “off the shelf,” modified, or customized

That is used TO increase, maintain, or improve function of individuals with disabilities.

- **GOAL:** to match an individual’s needs with specific ATEC to **enhance** person’s **capabilities** AND **quality of life**.
ATECH to assist in:

1. Computer accessibility
   • a great way to improve:
     • connection and communication

2. Communication
ATEC to Access Computers

1. Dictation Programs (free)
   • Mac & Windows
2. Eye-tracking devices
   • Camera Mouse (free)
3. Foot Mouse & Hands-Free Touchpad
4. The AirBar
“Accessibility” options for Mac
“Accessibility” options for Mac: Dictation demo
“Ease of Access” options: Windows
Prizmo: Optical Character Recognition (OCR) Software

1. take a photo of a magazine at the doctor’s office
2. convert the words to text
3. Use a dictation program on phone to change text-to-speech

www.macupdate.com/Prizmo
Eye Tracking

Pupil and Corneal Reflection is detected to calculate eye gaze
1. Dwell time
2. Sensitivity
3. Smoothing reduces the jerkiness if extrapyramidal tremors
Hands-Free Control of Computer

- The Foot Mouse (~$139)
Hands-Free Control of Computer
http://www.handsfreetouchpad.com/
difficulty using a standard mouse? Turn any screen into a touchscreen with… The AirBar – [www.air.bar](http://www.air.bar) (available for Mac & PC)
FOR A LIST OF FREE OR INEXPENSIVE AAC FOR APPLE/MAC IOS:

www.tbiloc.org/brain-education

to access this list!
Speech Generating Devices (SGD) “Higher tech” systems

May be covered by Medicare or other insurance under: “Durable Medical Equipment (DME)”

- Tobii I-Series (eye tracking SGD)
  » http://www.tobiidynavox.com/
- Eyegaze Edge Talker (eye tracking SGD)
  » http://www.eyegaze.com/
- Eye Tribe Tracker (eye tracking SGD)
  » https://theeyetribe.com/
Tobii Dynavox I-Series (SGD)
Medicare Compliant Eyegaze Edge Talker

• Physician/speech pathologist must “prescribe”
• Most insurances cover 80% of this device
• Unfunded, the price of the Eyegaze Edge is $8,700!
• LC Technologies
  – Medicare and Medicaid support
  – (703) 385-8800 [Cathy Fahmi]
The Eye Tribe Tracker

- $99
- Compatible with the following:
  - PC (Windows 7/8)
  - Mac (Lion 10.8.4)
- https://theeyetribe.com/
Next:

A Tour of Durable Medical Equipment (DME)

Ask your MediCare provider!


or call 1-800-MEDICARE (1-800-633-4227)

To find a Medicare DME provider near you.

One example in Orange County, CA:
Emporium Home Care (714 224 7474)
150 E Imperial Hwy. Fullerton, CA 92835
DME for Eating

Protège-vêtements
Avec attrape-miettes
Clothing Protector
with Crumb Catcher

- Facile à nettoyer
- Peut être ajusté à des positions multiples
- Couvre le haut du corps et les genoux

It's ESSENTIAL for Good Health!

Utensil Strap
- Fits most hands
- Ideal for individuals with limited grip

Eating / Drinking

Huntington's Disease
Society of America
What is the POWER OF RED?

Studies have shown that using red dinnerware increase eating for individuals with Alzheimer’s and Dementia.

Shows contrast between the table and food, allowing the user to recognize what they are using and eating.

Ideal for people who cannot tilt their head back due to neck injuries or choking.

Dishwasher and microwave safe.

MADE IN TAIWAN

2013 ESSENTIAL MEDICAL SUPPLY, INC.

DME for Eating
DME for Safety

The Car Handle
(Makes it easy to get in and out of the car)

No. 1170

Features & Benefits

- Installs and removes in seconds
- Fits any framed car window
- Strong nylon construction
- Adjustable length
- No-slip rubber ergonomics textured grip

Be Active Be Comfortable

Height Adjustable Hand Bed Rail

Extra Strong. Made of chrome plated steel
Extends a full three (3) feet under the mattress
Portable - easy to take with you when you travel

Gives you the “Helping Hand” you need to get in & out bed safely and securely

Great for all Beds including Pillow Top Models
DME for Safety

- Deluxe Inflatable Bed Shampoo Kit
  - Ideal for bed use
  - Easy to inflate
  - Portable convenience

- Toilet Support Rails
  - Provides secure support

Products for an Independent Life
DME for Exercise

pedal exerciser
- For upper or lower body strengthening
- Can be used on a table top or the floor
- Adjustable resistance control
- Chrome steel frame; non-skid base

ejercitador de pedales
- Para fortalecer los miembros superiores o inferiores del cuerpo
- Se puede utilizar sobre una mesa o el suelo.
- Control de resistencia regulable
- Estructura de acero cromado, agarraderas antideslizantes

exerciseur à pédales
- Pour renforcer la partie supérieure ou inférieure du corps
- Peut être utilisé sur une table ou le sol
- Contrôle ajustable de la résistance
- Construction en acier chromé, ensembles antiderapants

Exercise Pulley
- Helps restore upper body mobility
- Great low impact resistance workout
- Will fit over most doors

It's ESSENTIAL for Good Health!
The Walk-Bicycle

• Freezing of gait (FOG) is a common Parkinsonian symptom (HD Symptom)
  • “Shifting weight laterally” may cause problems with forward stepping movement
  • Bicycling avoids this, but not always feasible to ride & dismount.
    – walk-bicycle:
      • no pedals
      • lowered seat
      • may reduce FOG in some
  • Elliptical exercise machines take out the high impact and reduces the need to shift weight laterally

(Jacobs et al., 2009; Nutt et al., 2011; Stummer et al., 2015)
“Smarter” Furniture

1. Smarter furniture
   a. Hard plastic, instead of glass
   b. Rising furniture
   c. Chairs with assists
Physical Therapy Techniques
Physical Therapy (physiotherapy) and HD

- Physical Therapy areas of rehabilitation:
  - Gait/balance transfers
  - Strengthening/coordination
  - Postural stability (keeping still and moving)
    - Transferring body weight from one leg to the other
      - Lateral weight shifting
- Benefits to seeing a physical therapist:
  - Prevent falls
  - Promote correct walking/body control
  - Build coordination/flexibility
  - Facilitate confidence in body movement
- Exercises can be adapted for lying down, sitting, or standing.

(Bilney, Morris, & Perry, 2003; Busse, & Rosser, 2007; Zinzi, Salmaso, De Grandis, Graziani, Marceroni, Bentivoglio, Zappata, Frontali, & Jacopini, 2007)
How can Physical Therapists help HD

1. Teaching how to maintain energy
2. Aerobic exercises
3. Stretching exercises (avoid muscle tightness)
4. Strengthening/Balance exercises (prevent falls)
5. Assist with selecting DMEs and how to use them
6. Teach caregivers how to transfer
   – (e.g., car, bed, bathroom, chair)
“Hacks” for Daily Living
<table>
<thead>
<tr>
<th>Physical Movements</th>
<th>Eating</th>
<th>Sleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Engage in exercises</td>
<td>• Sitting up/good posture</td>
<td>• Good sleep hygiene</td>
</tr>
<tr>
<td>• Routine</td>
<td>• Slow to avoid choking</td>
<td>– Low/no light</td>
</tr>
<tr>
<td>• Safety</td>
<td>• DMEs to help chewing/drinking</td>
<td>– Same time</td>
</tr>
<tr>
<td></td>
<td>• Clock technique with caregiver</td>
<td>– Digestion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>– No loud abrupt sounds</td>
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</tbody>
</table>
Cognitive Strategies: Simplifying life

Using technology or not!
Common Cognitive Changes in HD

1. Memory & Learning
2. Perception
3. Executive Functioning
4. Language and communication
5. Among many others
Keeping my life organized

1. Minimize clutter
   1. cognitive and physical benefits
2. Determining order of activities for the day
3. Sort and prioritize
4. Maintain “Cognitive Clarity”
“Keeping clarity”

1. Remove distractions
2. Minimize input sources
3. Allow more time for tasks
4. Reduce quantity of information
5. Avoid open ended questions when frustrated
6. Do one thing at a time
   - “multitasking” some would say is a myth
7. Minimize excess stimulation
   - visual and auditory
Remembering tasks
Potential Solutions

1. Calendars
2. To do lists/ task lists
3. Regular routine/schedule
4. Reminder watches/ alarms
5. Set a single place in the home where all “lists” are kept
6. “Tile” is a locating hardware/software you can use
   - Put on your keys, purse, etc.
   - https://www.thetileapp.com/
7. Smartphone Apps
Cognitive supplementing apps for your iPhone & iPad

- Search Best Suite in the app store
- $9.99 for 3 apps:
  - Pace My Day
  - Reach My Goals
  - Strategize My Life

www.bestconnections.org
Task Lists

1. Task lists can be used to supplement memory
2. Can be paired with an alarm
3. Alarms can be set on watches or timers
4. As tasks are completed, crossed off list
5. Create a new list and review it each morning
Reminder Watches

- Reminder watches can be used as a reminder
- If you would like to try a Reminder Watch, try:

1. E-Pill Cadex Watches
2. VibraLite Watches
3. WobL Watches
4. Time Timer Watches
Slowing the decline: cognition apps

Brain Training Apps

Note: these apps have not been through Clinical Trials to cure, treat, or prevent disease

- **NeuroNation**
- **Lumosity**
  - Memory challenge
  - Brain training applications
  - Designed to help memory
NeuroNation and Lumosity App
Affective Neuroscience: What we can learn and how

- **Neuromechanisms of emotion:**
  - “positive & negative” parts of the brain
- **Neuroplasticity:**
  - brain is malleable based on what we think and do
  - Extend range of mental capabilities
    - Including training our minds to be happy
- **Frequent mental training strategies can produce change**
- **Psychosocial factors** play significant role in the modulating course of cardiovascular disease and asthma
  - Therefore, information from the environment gets “under the skin” and modulates ours brain in a significant way
Psychosocial Support Defined

Psychosocial support means:

a. the support that we get from friends, family, and even ourselves, to help us get and stay healthy.

How can I get it?

Talk therapy

a. individually or in a support group (HDSA.org & HDSAOC.org)

Educating yourself

a. about what you may be going through, or whatever may be causing stress.

Fun group activities (exercising, games, cooking, & eating!)

Benefits?

1. Reduced stress, depression, and anxiety.
2. Improved problem solving abilities – necessary when dealing with stress.
3. Increased resilience, or ability to adapt to new life changes

Caregivers who have poorer coping skills and more avoidance report lower life satisfaction when living with a loved one with a disability

(Pecillo, 2016; Spiegel, 1994)
Access The Files & Videos Discussed in this presentation

VISIT:

tbioc.org/brain-education

HDSAOC.org

www.tbioc.org/brain-education
The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2018 HDSA Convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.


References


References


