




Caregiver's CORNER

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Caregiver's Corner

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Caregiver's Corner Webinar, February 22, 2011
Team Care for Huntington's disease

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Team Care for Huntington's disease

- Why?
- What are the components of team care?
- How to find/create a health care team



Care-defining features of HD

- Adult-onset (usually)
- Genetic disorder
- Movement disorder
- Psychiatric/behavioral disorder
- Dementing disorder
- Degenerative (progressive) over years to decades
- Purely neurological (does not affect other organs)
- Fatal



Goals of treatment

- Reduce burden of symptoms
- Maximize function
- Optimize quality of life



HD health professionals


- Neurologist
- Psychiatrist
- Psychologist
- Neuropsychologist
- Genetic counselor
- Social worker
- Nurse (case manager)
- Research team
- Physical therapist
- Occupational therapist
- Speech therapist
- Dietician
- Chaplain
- Hospice team
- Primary care physician
- Dentist

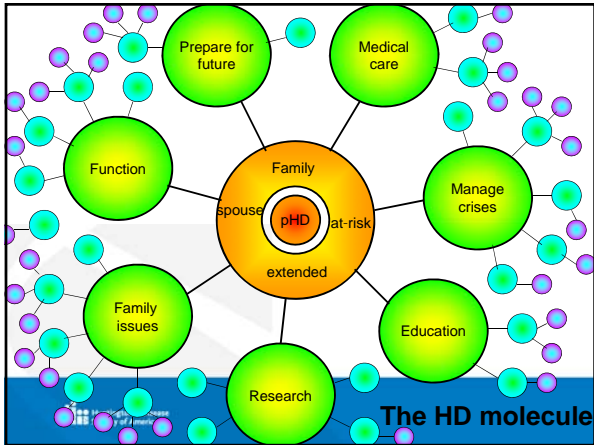


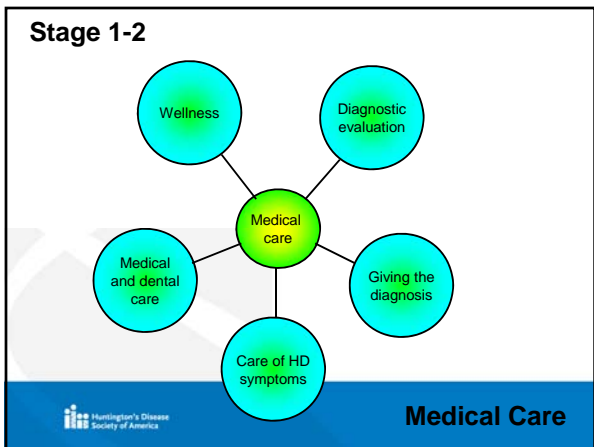
Shoulson-Fahn functional capacity scale

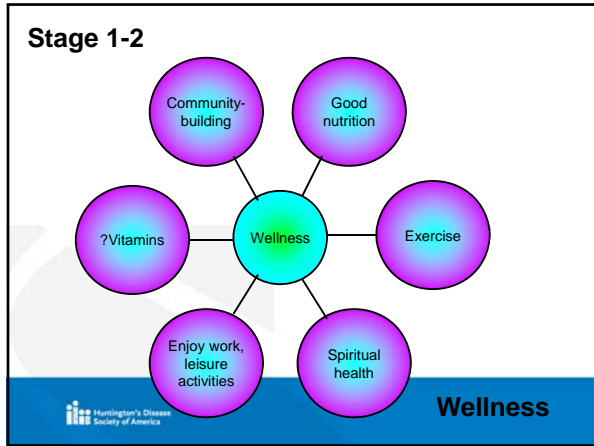
- **Work**
 - 3-2-1-0
- **Money**
 - 3-2-1-0
- **Chores**
 - 2-1-0
- **Self-cares**
 - 3-2-1-0
- **Live**
 - 2-1-0

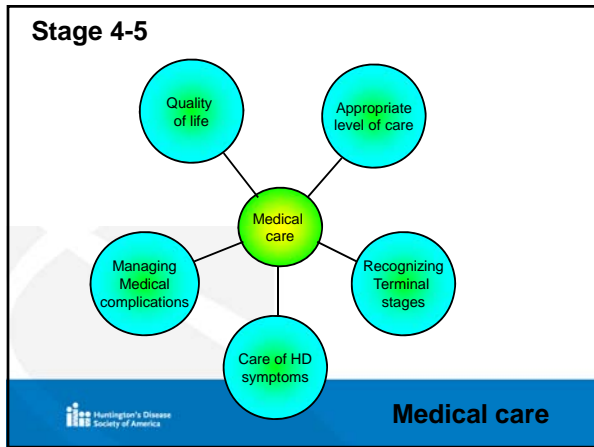
- Maximum: 13 points
- 11-13: Stage 1
- 7-10: Stage 2 } early
- 3-6: Stage 3 transitional
- 1-2: Stage 4 } late
- 0: Stage 5

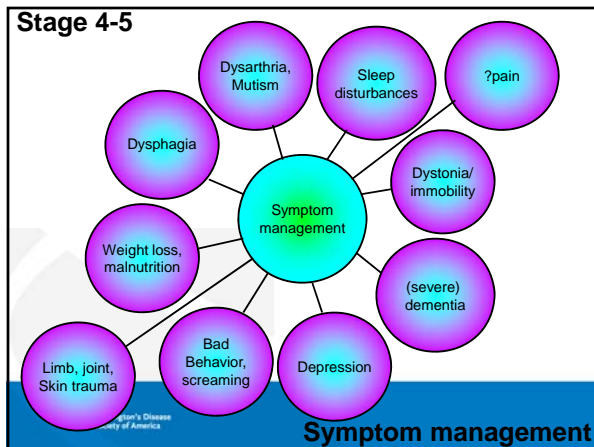


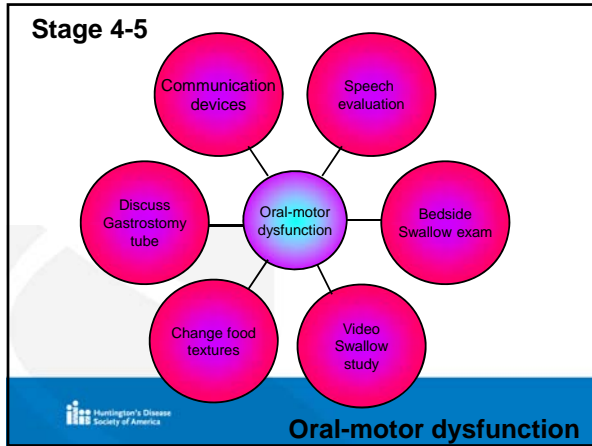


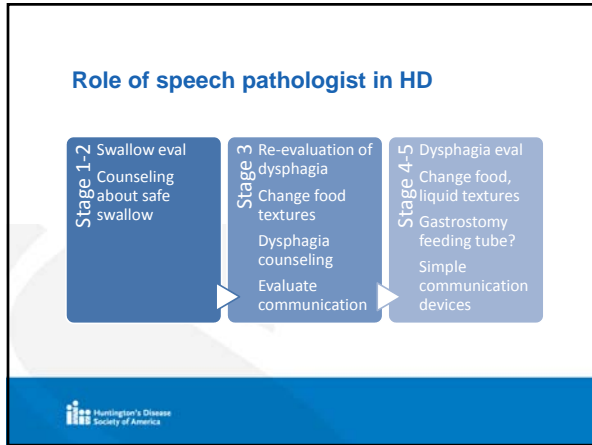


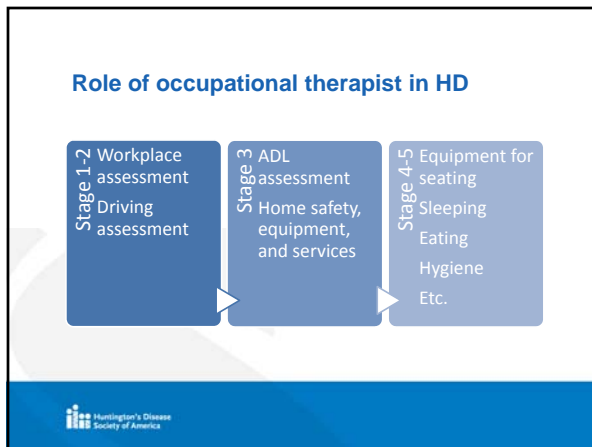












Role of dietician in HD management

Stage 1 Nutritional assessment
General "healthy eating in HD recommendations"
Identify financial, psychological barriers to healthy eating

Stage 3 Assist speech pathologist in food texture recommendations
Calorie counts
Add high-calorie supplements if needed

Stage 4 Translate texture recommendations into specific food recommendations
High calorie supplements
Tube feeding preparations

Huntington's Disease Society of America

Role of primary care physician in HD

Stage 1 Usual preventive health measures (vaccinations, mammography, etc)
General primary care

Stage 3 General primary care

Stage 4 Manage medical complications
• Infections
• Vitamin deficiencies
• Skin breakdown
• Broken bones
Liaise with hospice team

Huntington's Disease Society of America


How to create a care team

- Centers of Excellence

Huntington's Disease Society of America


How to create a care team

- Physician's Guide to HD
 - Third edition to be published this summer
 - Useful for patients and families
 - Bring a copy to the doctor!
 - On-line and print editions will be available



How to create a care team

- Network with other families in the area
 - Identify interested physicians
 - Identify available services
- Ask about referrals to rehabilitation therapists
- Use HD Chapter social workers
- Genetic counselors are at most medical schools
- Speak up for yourself!



Questions & Discussion



Questions

- Questions will be answered after the presentation.
- However, you may send a question anytime during the presentation.
- To send a question, go to the control panel that appears on the right side of your screen.
- There will be a panel for typing in a question.
- After typing your question, hit the "send" button



To View this Webinar Again

- Approximately 48-72 hours after this webinar is broadcast, you will be able to access it for viewing on the HDSA national website.
- To access this presentation, go to www.hdsa.org and scroll down the home page until you come to the link for the webinar. There will be an accompanying Powerpoint presentation that will allow you to print the slides out as well as a PDF file of additional information.
- Older webinars are archived in the *Living with HD* section.