



Management of midstage HD

Martha A. Nance MD

Hennepin County Medical Center HD COE

Struthers Parkinson's Center



Huntington's Disease
Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2011 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.

Presenter Disclosures

Martha Nance

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

**No relationships to disclose
or list**



**Huntington's Disease
Society of America**

Clinical features of HD

- Clinical aspects
 - Movement disorder
 - Involuntary movements
 - Voluntary movements
 - Cognitive disorder
 - Emotional disorder
 - Wide range of symptoms
 - (weight loss)



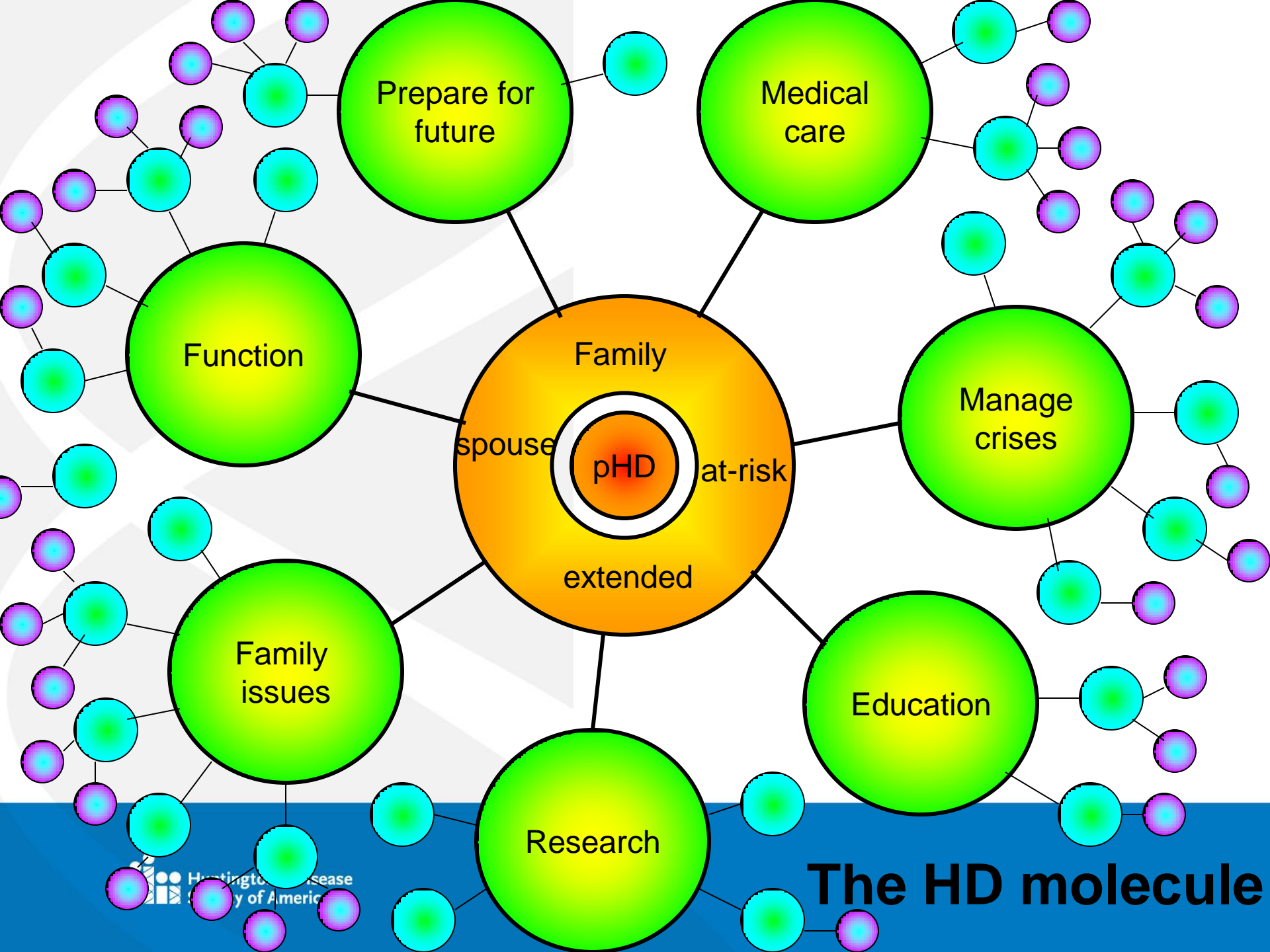
Stages of HD

- Shoulson-Fahn scale
 - Assesses work (0-3), money (0-3), chores (0-2), ADLs (0-3), Residence (0-2)
 - Stage 1 (11-13)—work, relationships, diagnosis
 - Stage 2 (7-10)—dx, driving, work, enjoyment
 - Stage 3 (3-6)—transition time: personal help needed
 - Stage 4 (1-2)—in-home help vs. nursing home
 - Stage 5 (0)—dignity in late stages; terminal/hospice

Principles of management-team-based care

Neurologist or psychiatrist
Psychology,
neuropsychology
PT, OT, speech
Nurse-case manager
Social worker
Genetic counselor
Dietitian

Chaplain
Medical doctor
Dentist
Research team
Nursing home staff
Lay group volunteers



Prepare for future

Medical care

Function

Family

Manage crises

pHD

at-risk

extended

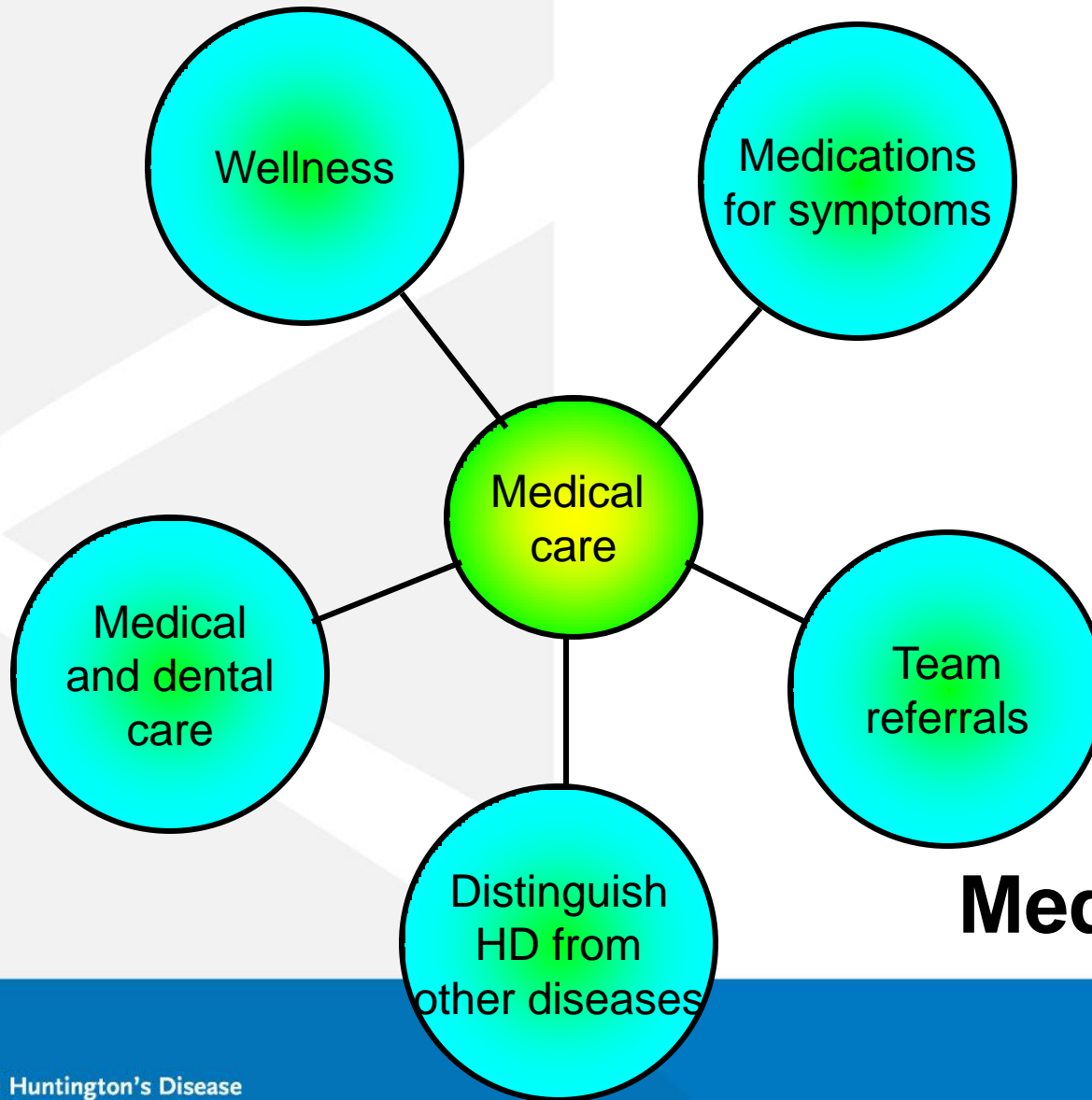
spouse

Family issues

Education

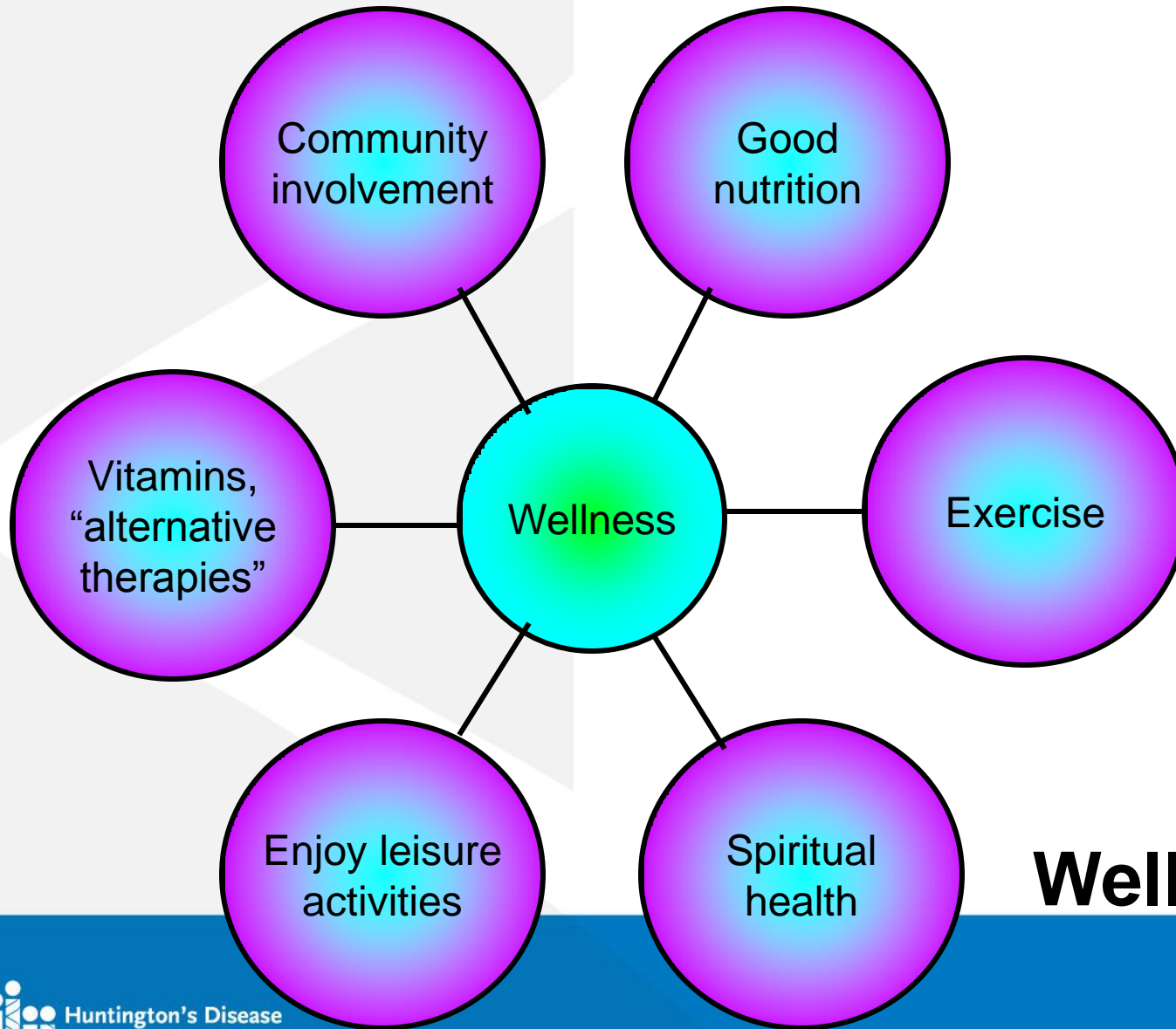
Research

Stage 3



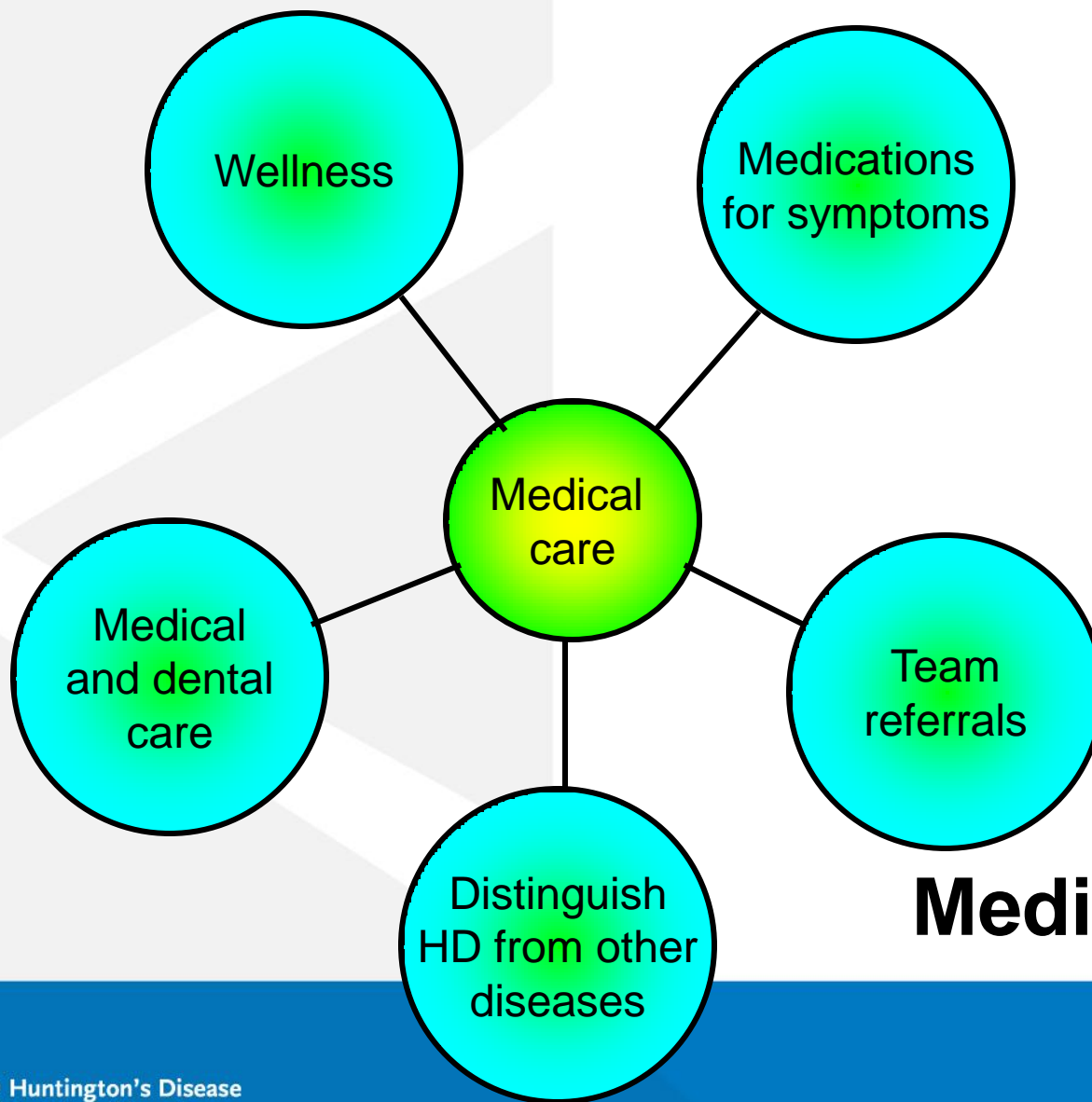
Medical Care

Stage 3



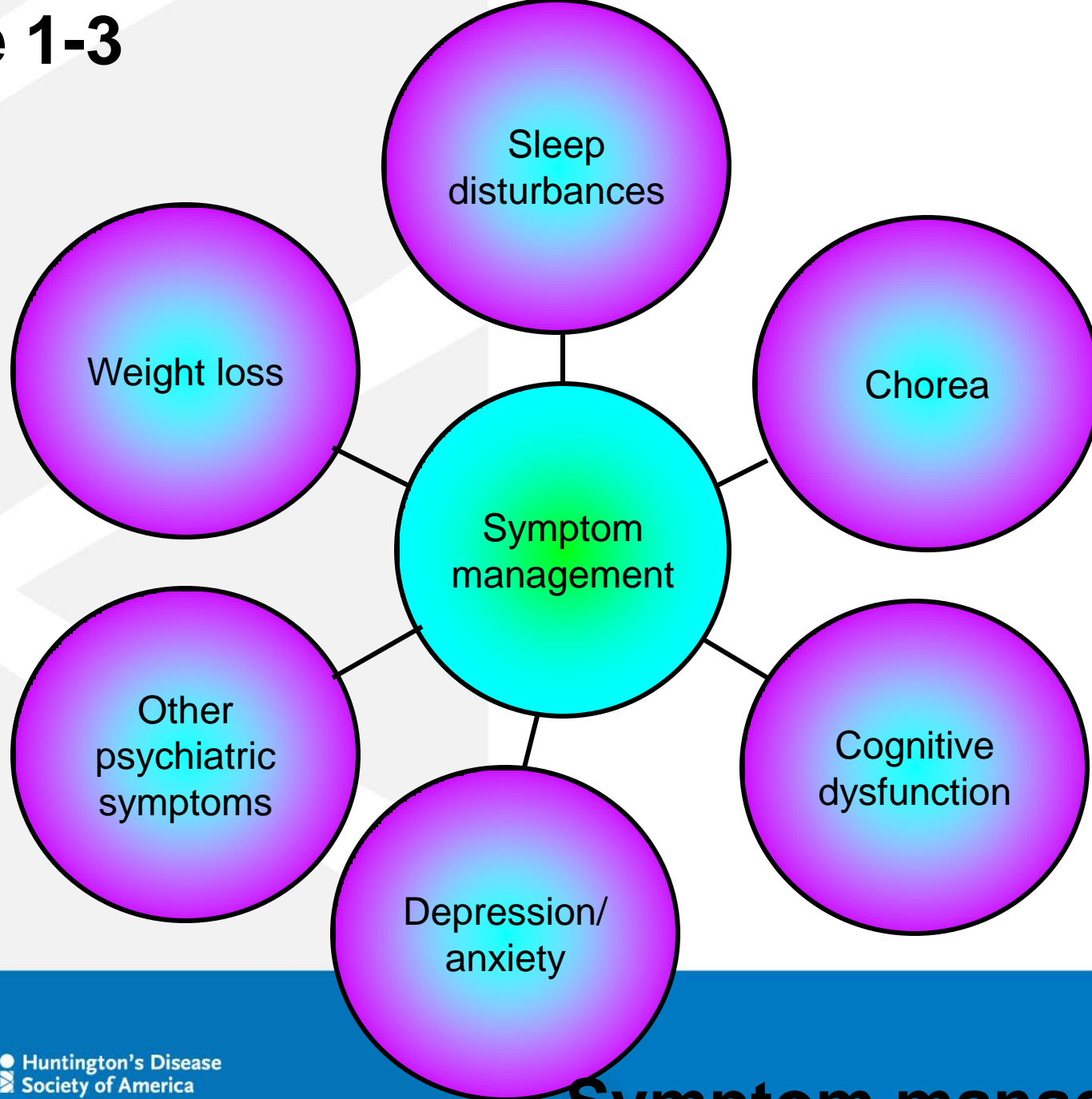
Wellness

Stage 3

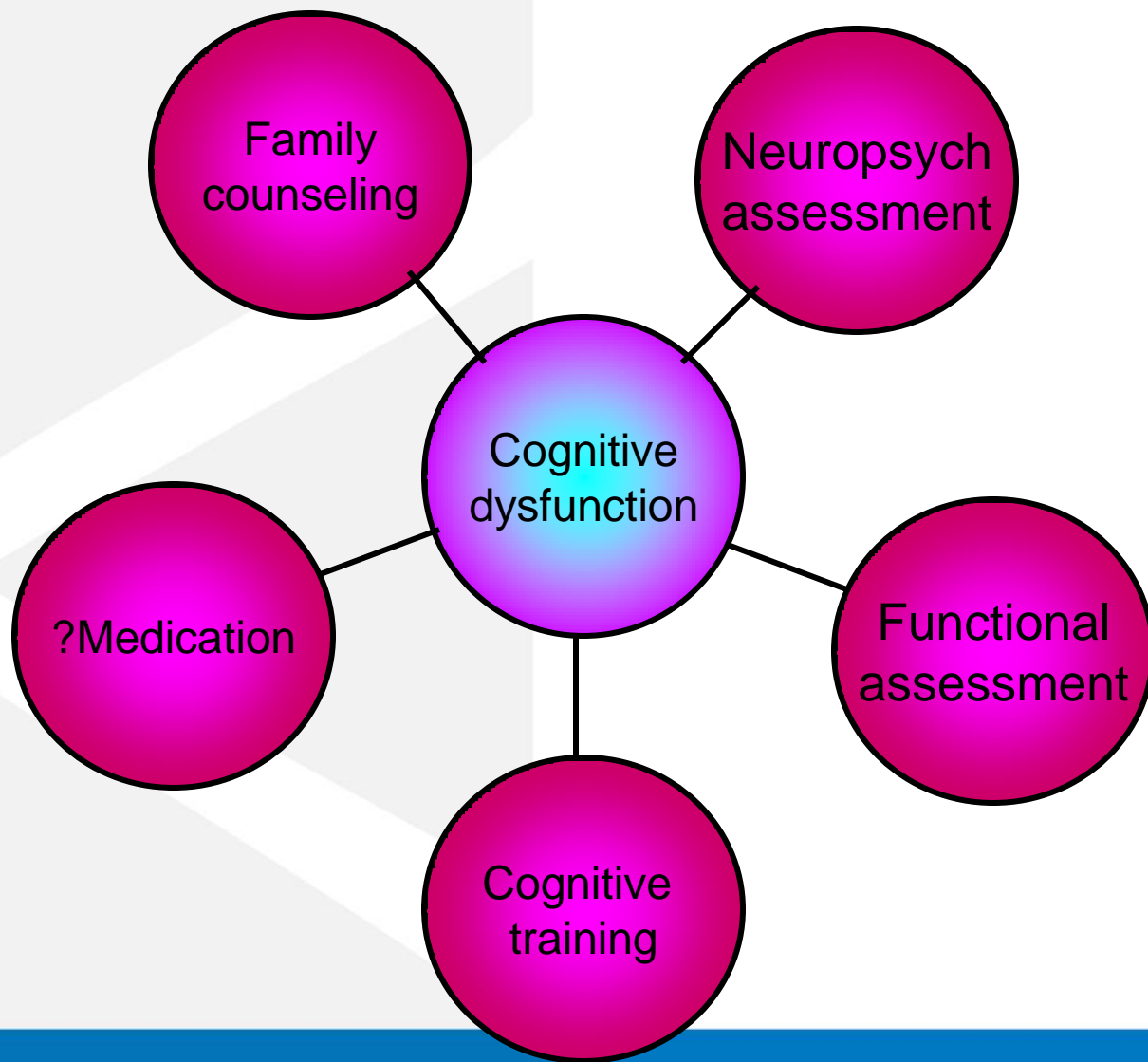


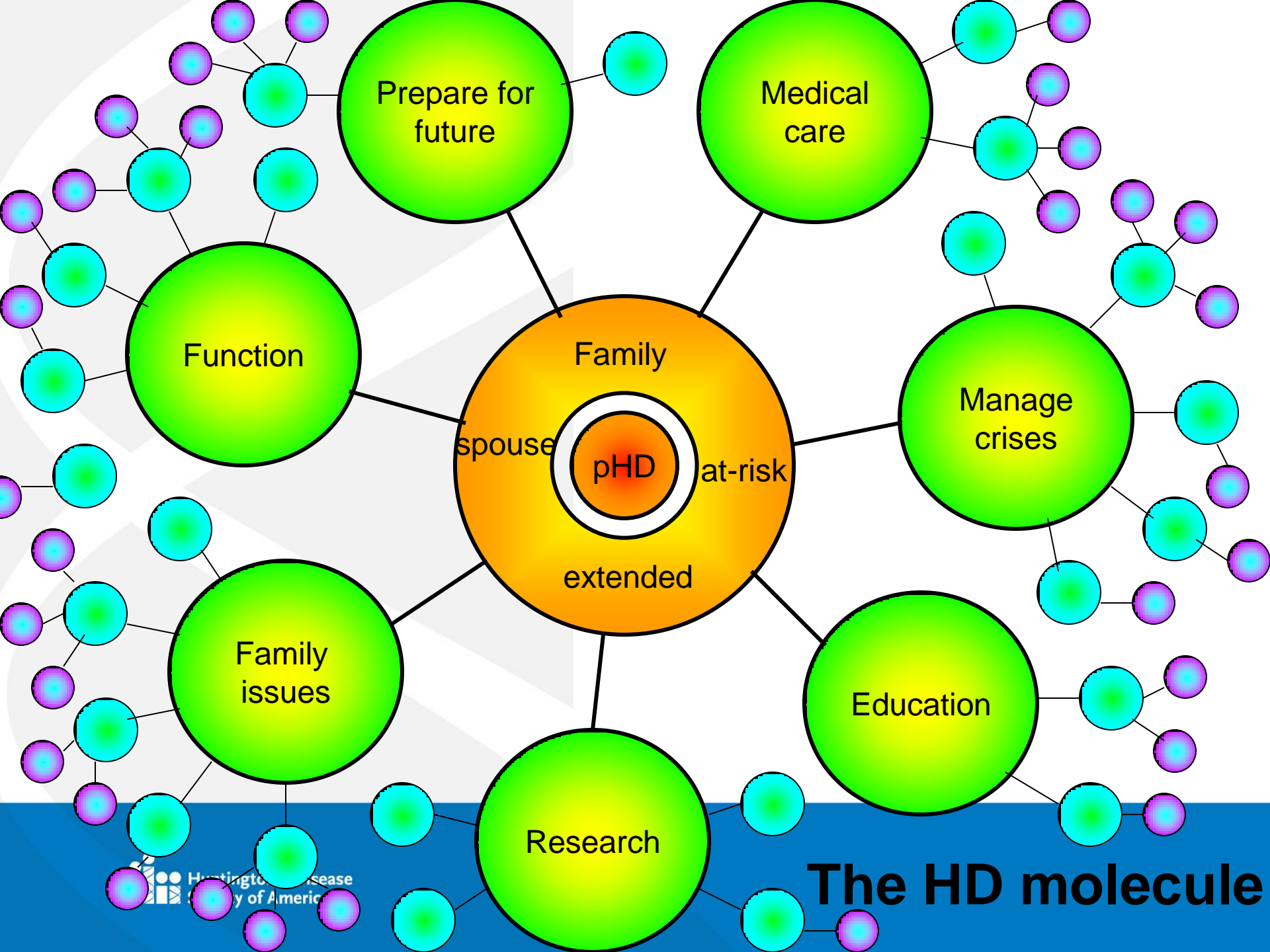
Medical care

Stage 1-3



Stage 1-4





Prepare for future

Medical care

Function

Family

Manage crises

pHD

at-risk

spouse

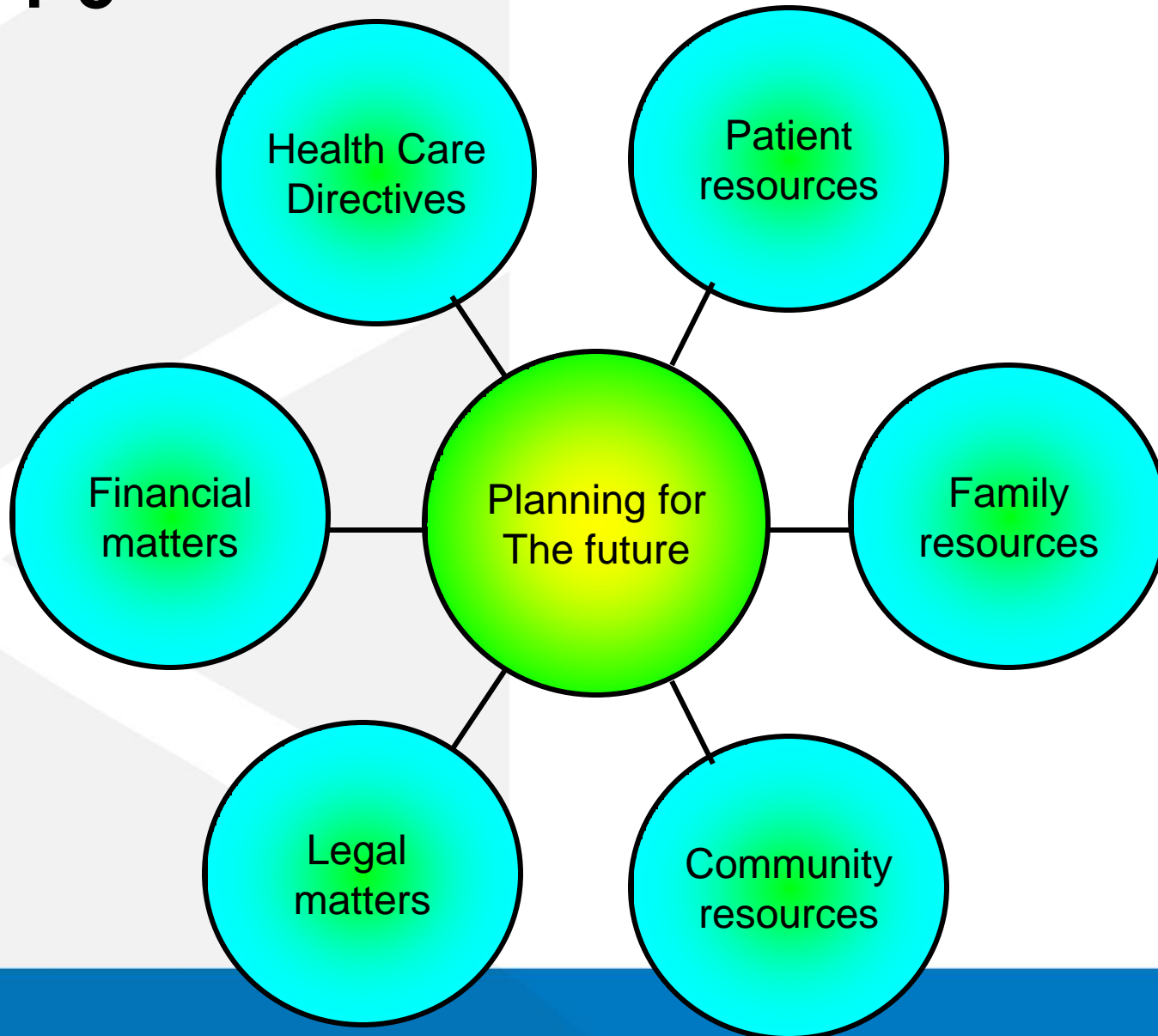
extended

Family issues

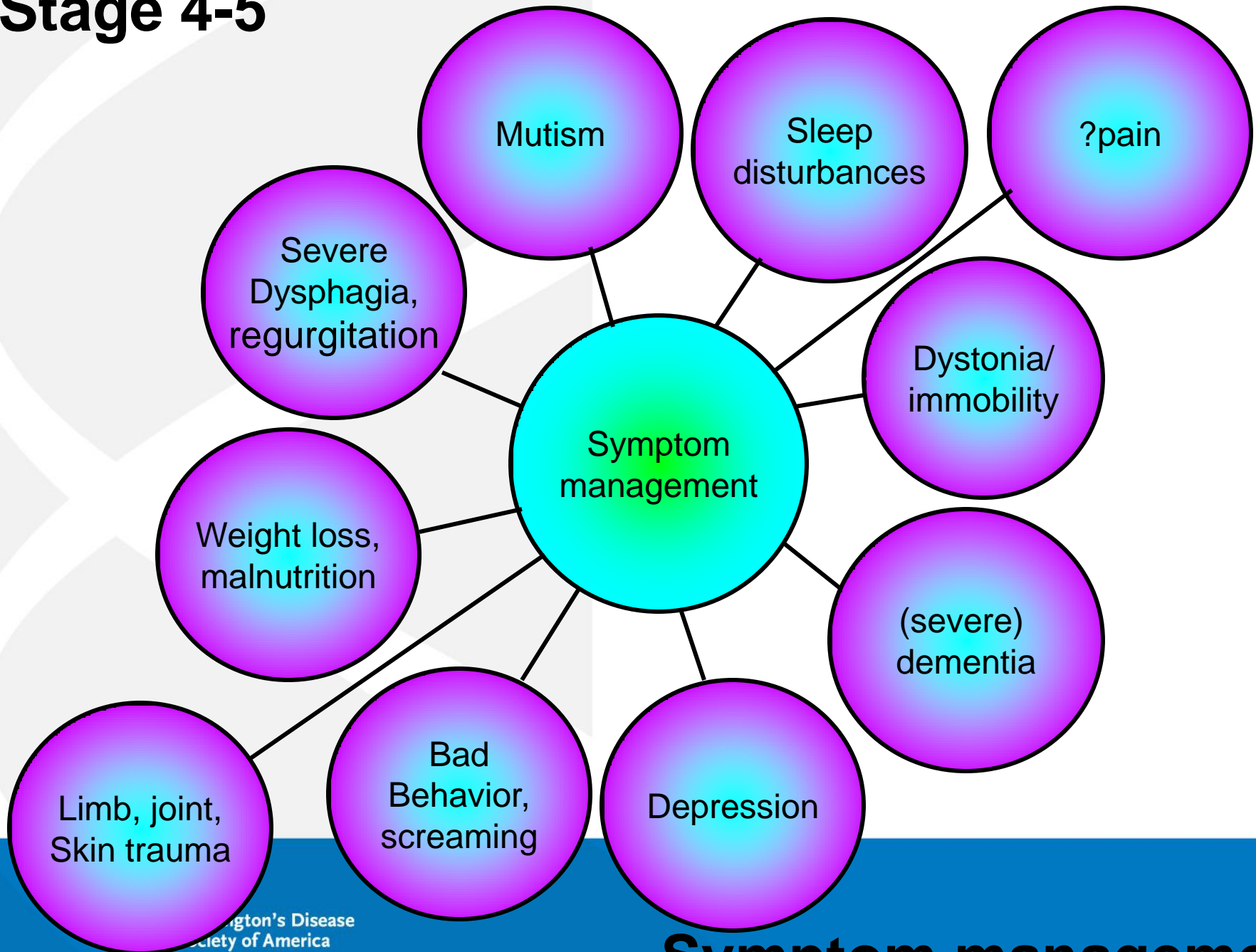
Education

Research

Stage 1-5



Stage 4-5



Medications for HD

- Chorea
 - Neuroleptics (haloperidol, thiothixene, chlorpromazine)
 - Atypical neuroleptics (risperidone, olanzapine)
 - Tetrabenazine (FDA-approved for HD)
- Depression, anxiety, paranoia, explosive behavior, irritability, hallucinations
 - Many drugs
- Cognitive dysfunction
 - (Alzheimer's drugs: donepezil, memantine, others)
- Weight loss
 - Eat!

Vitamins (and other unproven treatments)

- Probably won't hurt, might help
 - Multivitamin, B, E (<400 IU), Coenzyme Q10 (>1000mg—expensive), omega fatty acids, creatine
- Probably won't hurt, probably won't help
 - Blueberries in human doses, most nutraceuticals, blue-green algae, acai berries,...

Vitamins and other unproven treatments

- I don't know what it is or why it would help
 - Mangosteen, vinpocetine, homeopathy, etc etc
- Sure, why not?
 - Yoga, massage, acupuncture (if appropriate symptoms), tai chi, “Eastern medicine” (done appropriately)
- And there's exercise, eat right, sleep right, avoid excess caffeine, nicotine, alcohol...

Centers of Excellence

- Designated by HDSA
- 21 Centers throughout the country with special expertise in HD
- COEs have multidisciplinary care, support services, research
- HCMC HD Clinic is an HDSA COE

You are not alone...

- Care
- Family support
- Genetic testing
- Advocacy
- Fundraising
- Research
- Community