Huntington's Disease Society of America

The Caregiving Journey…. Discussions to Increase Caregiver Quality of Life

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Presenter Disclosures

Stephanie Bernander

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

No relationships to disclose
or list

Thank you

HDSA – for letting me share my story and research

HDSA Wisconsin Chapter – Support through the journey

Jean Morak, HDSA Wisconsin Chapter Social Worker

Dr. Janet Williams, University of Iowa – research on day to day function in people with prodromal HD and family caregiving by adults and adolescents

My dad

Our time together today…..

- About me
- My Story
- The Research
- Next Steps

My Story

William Holcomb

My Story

Pre-1997	Grandparents on my dad's side had died prior to my birth Uncle had very strange movement disorder
1997	Dad wrote and indicated he had a genetic disease called Huntington's disease
2002	Dad came to visit for extended care
	The Caregiving Journey • HDSA Wisconsin Chapter • Finding place to live • Finding doctors, sorting out meds • Access to hospice • In-home care
2011	Eternal rest

My Story

My Story

WHERE DO PEOPLE GO FOR HELP?

WHAT AM I MISSING?

THIS IS REALLY, REALLY HARD!!!!!

IT MIGHT BE EASIER IF I JUST HAD THE RIGHT HELP……

Your Turn

- If you would like to….find someone sitting next to you and share out how your situation may have been the same or different from mine.

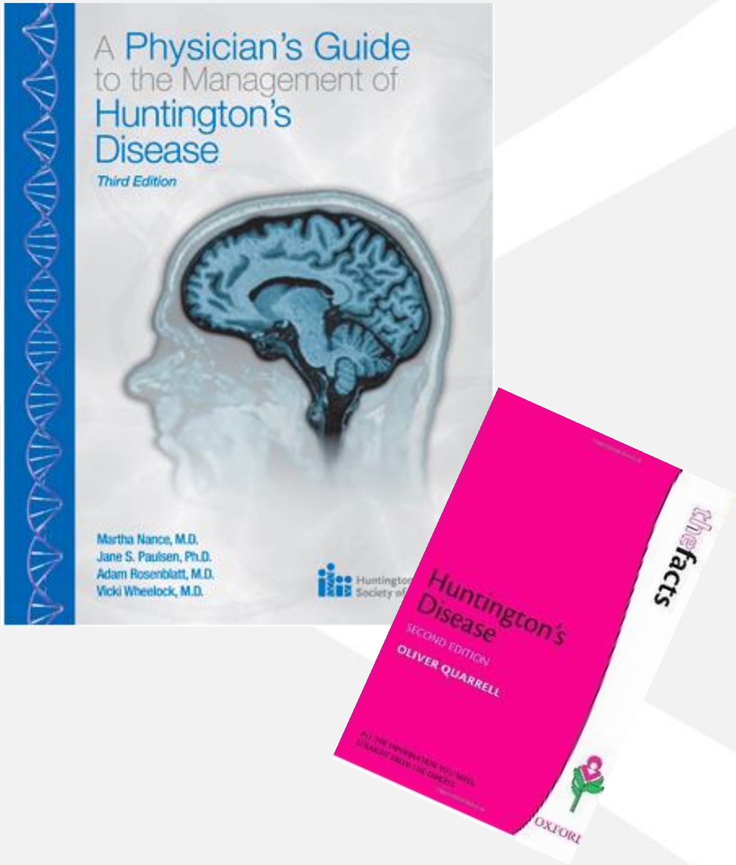
- What is/was your driving question?

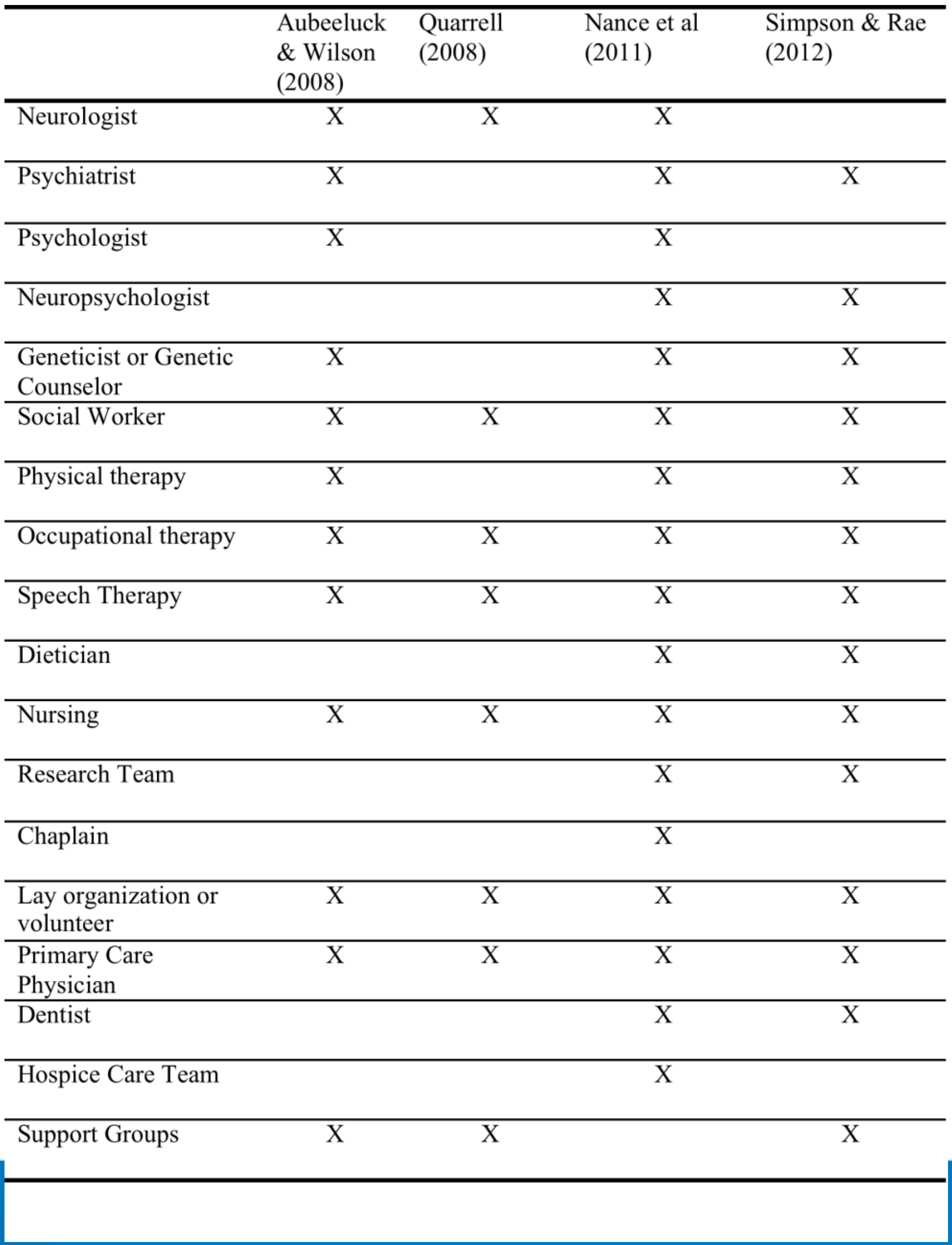
The Research

Access to Services for the Care of Huntington's Disease Patients and Caregiver Quality of Life

- What resources are accessed at various stages in the progression of HD?
- To what extent do caregivers use palliative care resources?
- What demographic characteristics affect caregiver access to resources and quality of life?
- How does access to resources affect caregiver quality of life?

Recommended services to access





	Aubeeluck & Wilson (2008)	Quarrell (2008)	Nance et al (2011)	Simpson & Rae (2012)
Neurologist	X	X	X	
Psychiatrist	X		X	X
Psychologist	X		X	
Neuropsychologist			X	X
Geneticist or Genetic Counselor	X		X	X
Social Worker	X	X	X	X
Physical therapy	X		X	X
Occupational therapy	X	X	X	X
Speech Therapy	X	X	X	X
Dietician			X	X
Nursing	X	X	X	X
Research Team			X	X
Chaplain			X	
Lay organization or volunteer	X	X	X	X
Primary Care Physician	X	X	X	X
Dentist			X	X
Hospice Care Team			X	
Support Groups	X	X		X

Access to suggested Palliative Care Resources

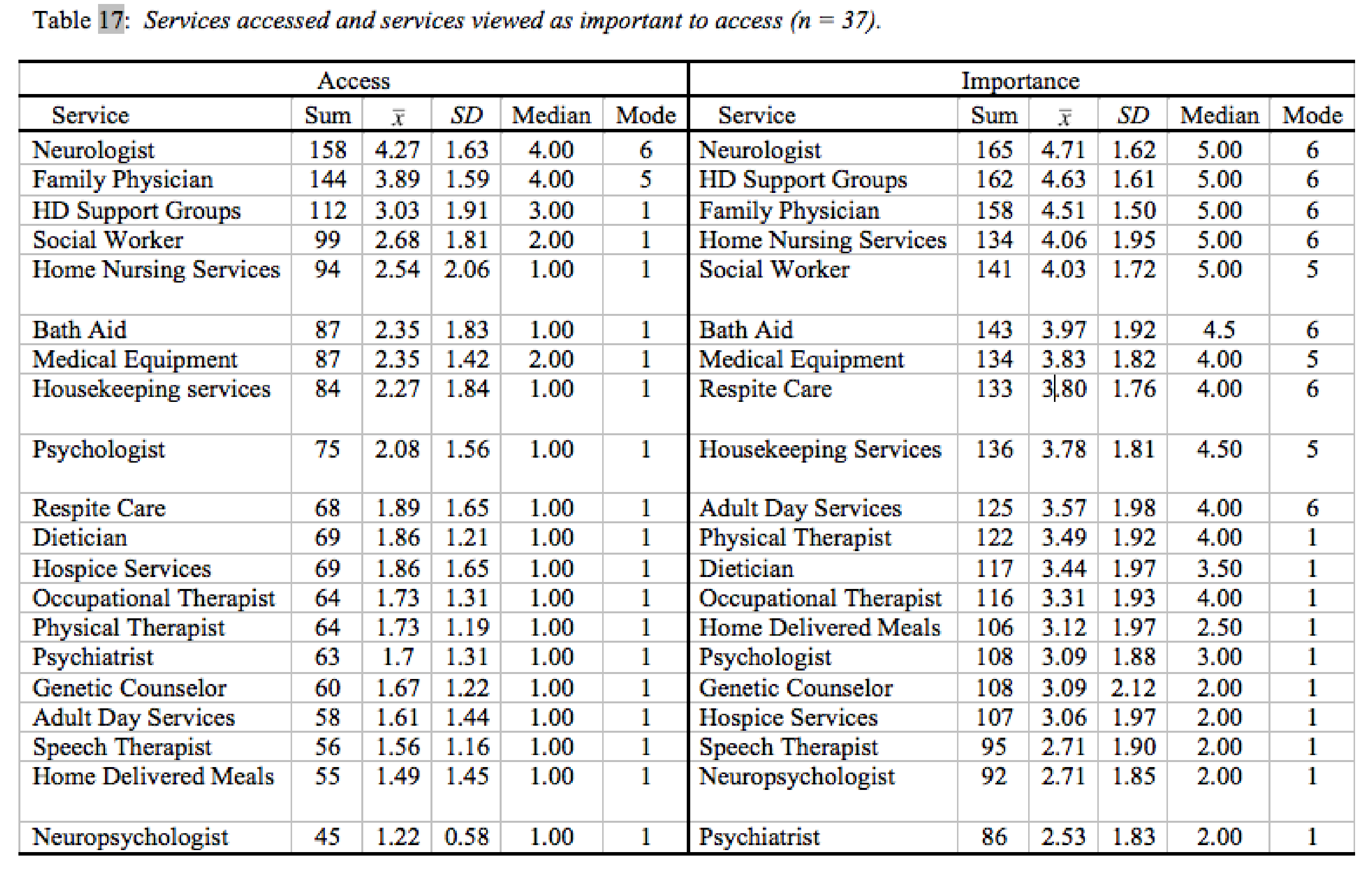
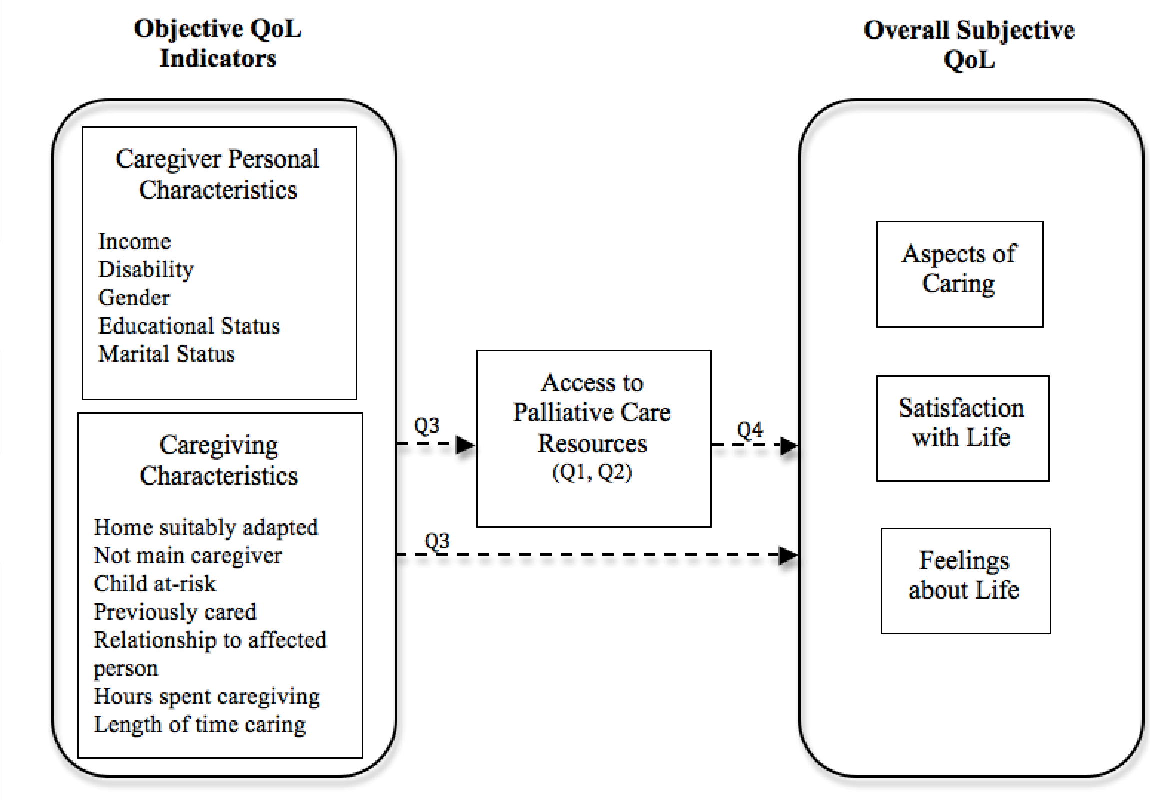


Table 17: *Services accessed and services viewed as important to access (n = 37).*

Access						Importance					
Service	Sum	$\bar{x}$	*SD*	Median	Mode	Service	Sum	$\bar{x}$	*SD*	Median	Mode
Neurologist	158	4.27	1.63	4.00	6	Neurologist	165	4.71	1.62	5.00	6
Family Physician	144	3.89	1.59	4.00	5	HD Support Groups	162	4.63	1.61	5.00	6
HD Support Groups	112	3.03	1.91	3.00	1	Family Physician	158	4.51	1.50	5.00	6
Social Worker	99	2.68	1.81	2.00	1	Home Nursing Services	134	4.06	1.95	5.00	6
Home Nursing Services	94	2.54	2.06	1.00	1	Social Worker	141	4.03	1.72	5.00	5
Bath Aid	87	2.35	1.83	1.00	1	Bath Aid	143	3.97	1.92	4.5	6
Medical Equipment	87	2.35	1.42	2.00	1	Medical Equipment	134	3.83	1.82	4.00	5
Housekeeping services	84	2.27	1.84	1.00	1	Respite Care	133	3.80	1.76	4.00	6
Psychologist	75	2.08	1.56	1.00	1	Housekeeping Services	136	3.78	1.81	4.50	5
Respite Care	68	1.89	1.65	1.00	1	Adult Day Services	125	3.57	1.98	4.00	6
Dietician	69	1.86	1.21	1.00	1	Physical Therapist	122	3.49	1.92	4.00	1
Hospice Services	69	1.86	1.65	1.00	1	Dietician	117	3.44	1.97	3.50	1
Occupational Therapist	64	1.73	1.31	1.00	1	Occupational Therapist	116	3.31	1.93	4.00	1
Physical Therapist	64	1.73	1.19	1.00	1	Home Delivered Meals	106	3.12	1.97	2.50	1
Psychiatrist	63	1.7	1.31	1.00	1	Psychologist	108	3.09	1.88	3.00	1
Genetic Counselor	60	1.67	1.22	1.00	1	Genetic Counselor	108	3.09	2.12	2.00	1
Adult Day Services	58	1.61	1.44	1.00	1	Hospice Services	107	3.06	1.97	2.00	1
Speech Therapist	56	1.56	1.16	1.00	1	Speech Therapist	95	2.71	1.90	2.00	1
Home Delivered Meals	55	1.49	1.45	1.00	1	Neuropsychologist	92	2.71	1.85	2.00	1
Neuropsychologist	45	1.22	0.58	1.00	1	Psychiatrist	86	2.53	1.83	2.00	1

Quality of Life



Objective QoL Indicators

Caregiver Personal Characteristics

- Income
- Disability
- Gender
- Educational Status
- Marital Status

Caregiving Characteristics

- Home suitably adapted
- Not main caregiver
- Child at-risk
- Previously cared
- Relationship to affected person
- Hours spent caregiving
- Length of time caring

Access to Palliative Care Resources (Q1, Q2)

Overall Subjective QoL

- Aspects of Caring
- Satisfaction with Life
- Feelings about Life

Aspects of Caring – HDQoL-C (Aubeeluck & Buchanan, 2007)

Question	Mean (0-10 scale)
How satisfied are you with the support you get?	5.00
How often is your life restricted by the need to maintain a daily regimented daily routine for the HD person you care for?	4.17
How often do you receive appropriate help from social services?	3.38
How often do you have access to professionals that have specialized knowledge of HD and understand its implications?	5.43
How much support are you given by healthcare professionals?	6.26
How often do the genetic consequences of HD impact upon your caring role?	3.88
How often do you have access to appropriate care facilities?	4.52
How often do you receive the necessary support you need?	4.74
How often do you experience a conflict of interest between what you want and what your HD affected relative wants?	4.05
How often do you sleep well?	4.36

Feelings About Life - HDQoL-C (Aubeeluck & Buchanan, 2007)

I feel.....	
guilty	5.81
financially disadvantaged	4.90
isolated	5.33
there is hope for the future	5.64
exhausted	3.60
supported	6.19
sad or depressed	5.36
stressed	3.48
worried about the genetic consequences of HD	2.90
my own needs are not important to others	4.83
comforted by the belief that one day there will be a cure for HD	4.57
that HD brought something positive to my life	3.45
comforted by my beliefs (religious, philosophical or spiritual)	7.12
that I can cope	7.12
that HD has made me a stronger person	6.76
that I have had a "duty of care" forced on me	5.31
like I don't know who I am anymore	6.5

Satisfaction With Life - HDQoL-C (Aubeeluck & Buchanan, 2007)

How satisfied are you with…..	Mean (0-10 scale)
your health?	5.79
what you achieve in life?	6.31
your close relationships with family or friends?	7.67
how safe you feel?	7.69
feeling part of your community?	6.57
your own happiness?	6.60
the treatment that your HD affected relative receives?	6.60
your overall quality of life?	6.38

Difficulty Experienced

- Falls (difficulty walking, mobility issues)
- Anger/violent outbursts
- Behavior
- Eating/Feeding
- Speech
- Continence
- Memory/dementia
- Emotional

Important to access but not currently accessing

- Home nursing services
- Social worker
- Bath aid
- Medical equipment
- Respite care
- Housekeeping services
- Adult day services
- Physical therapist
- Dietician
- Occupational therapist
- Psychologist

Not viewed as important to access

- Home delivered meals
- Genetic counselor
- Hospice Services
- Speech Therapist
- Neuropsychologist
- Psychiatrist

Summary of Results

- Services accessed at various stages include neurologist and family physician.
- HD support groups are accessed at beginning stages of the disease
- Other palliative care resources are accessed only to a limited extent
- Caregivers indicated that is was important to access a much broader range of palliative care services than those currently being accessed
- QoL scores declined some with length of time since diagnosis
- There was no significant relationship between overall QoL and total access to resources (But I wonder if that is because participants were not accessing a palliative care model for support)

More results

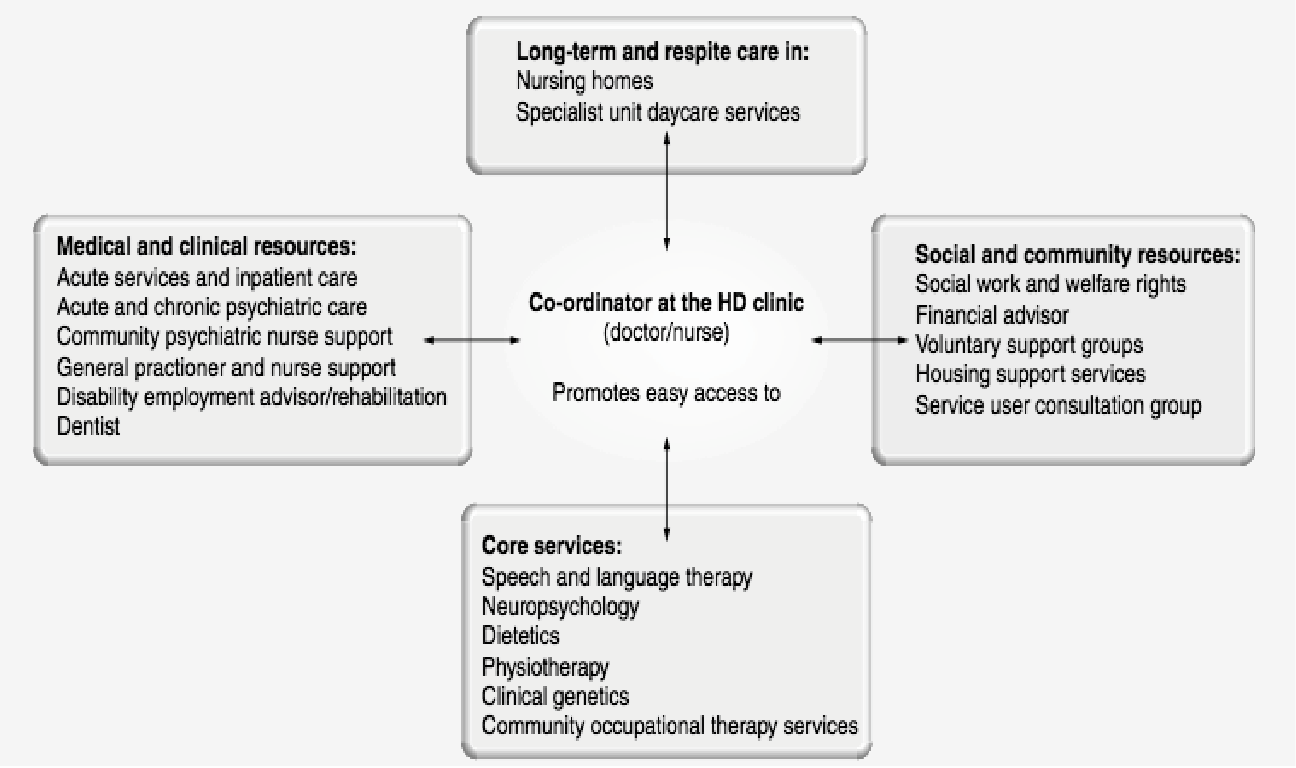
- While access to services is limited, caregivers seem to be somewhat satisfied with the care that they do receive.
- The results of the study reflect caregiver resilience, even when facing the serious consequences of HD to a relative.
- HD caregivers typically responded that they were positively influenced by close relationships, felt part of the community, and were satisfied with their own achievements.
- HD caregivers tend to be optimistic, accepting HD as part of their lives, find the good that can come from the disease, and providing the best possible care even though they do not optimally access suggested resources.

Your Turn

- How does this information relate to your situation?

Next Steps

- Model of a Managed Care Network - European Huntington's Disease Network



Long-term and respite care in:
Nursing homes
Specialist unit daycare services

Medical and clinical resources:
Acute services and inpatient care
Acute and chronic psychiatric care
Community psychiatric nurse support
General practioner and nurse support
Disability employment advisor/rehabilitation
Dentist

Co-ordinator at the HD clinic
(doctor/nurse)

Promotes easy access to

Social and community resources:
Social work and welfare rights
Financial advisor
Voluntary support groups
Housing support services
Service user consultation group

Core services:
Speech and language therapy
Neuropsychology
Dietetics
Physiotherapy
Clinical genetics
Community occupational therapy services

Next Steps – Achieving a palliative care model

- HD added to the list of Compassionate Allowances (2012)
- HD Parity Act – to access Medicare
- Revoke of the ‘improvement standard’ that limited skilled therapy and nursing service to those that would make long-term improvement in their conditions (2012)
- Rethinking Hospice Care
- Sign up for the survey of care needs for the upcoming meeting with the FDA.

Next Steps – Improving Caregiver QoL

- Verified what I was feeling as a caregiver. I didn’t have answers and that was OK.
- Build your network…..reach out
- HD Support Groups
- HDSA Webinars
- Think outside the box – connecting with others with similar disease situations
- Books and such
- “Not focus on what was broken or lost – but focus on what I can do” (Billy McLaughlin)
- “We might not have a cure, but we can cure the ignorance”

Your Turn

- What can I take away from this workshop to help me as a caregiver?

Finnish word meaning strength of will, determination, perseverance, and acting rationally in the face of adversity. It is defined by long-term rather than momentary courage. The ability to decide on a course of action and stick to it against repeated failures. It is bravado and bravery, ferocity and tenacity, the ability to keep fighting after most people would have quit, and to fight with the will to win.

Ours is not the task of fixing the entire world all at once, but of stretching out to mend the part of the world that is within our reach. Any small, calm thing that one soul can do do help another soul, to assist some portion of this poor suffering world, will help immensely.

- Clarissa Pinkola Estes