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Frontotemporal Degeneration Advances in Care & Support

Annual AFTD Education Conference
April 13, 2018

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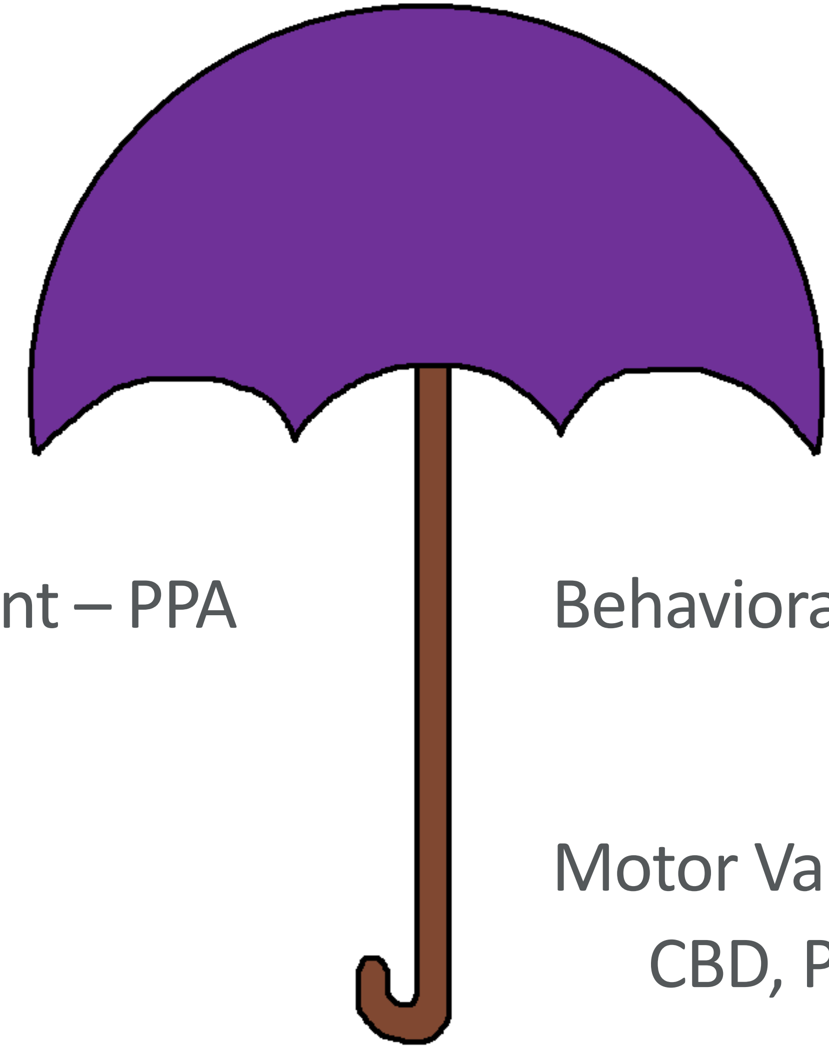
Cognitive Neurology and Alzheimer's Disease Center

Frontotemporal Disorders - FTD



Language Variant – PPA

- Logopenic
- Semantic
- Aggramatic

Behavioral variant FTD

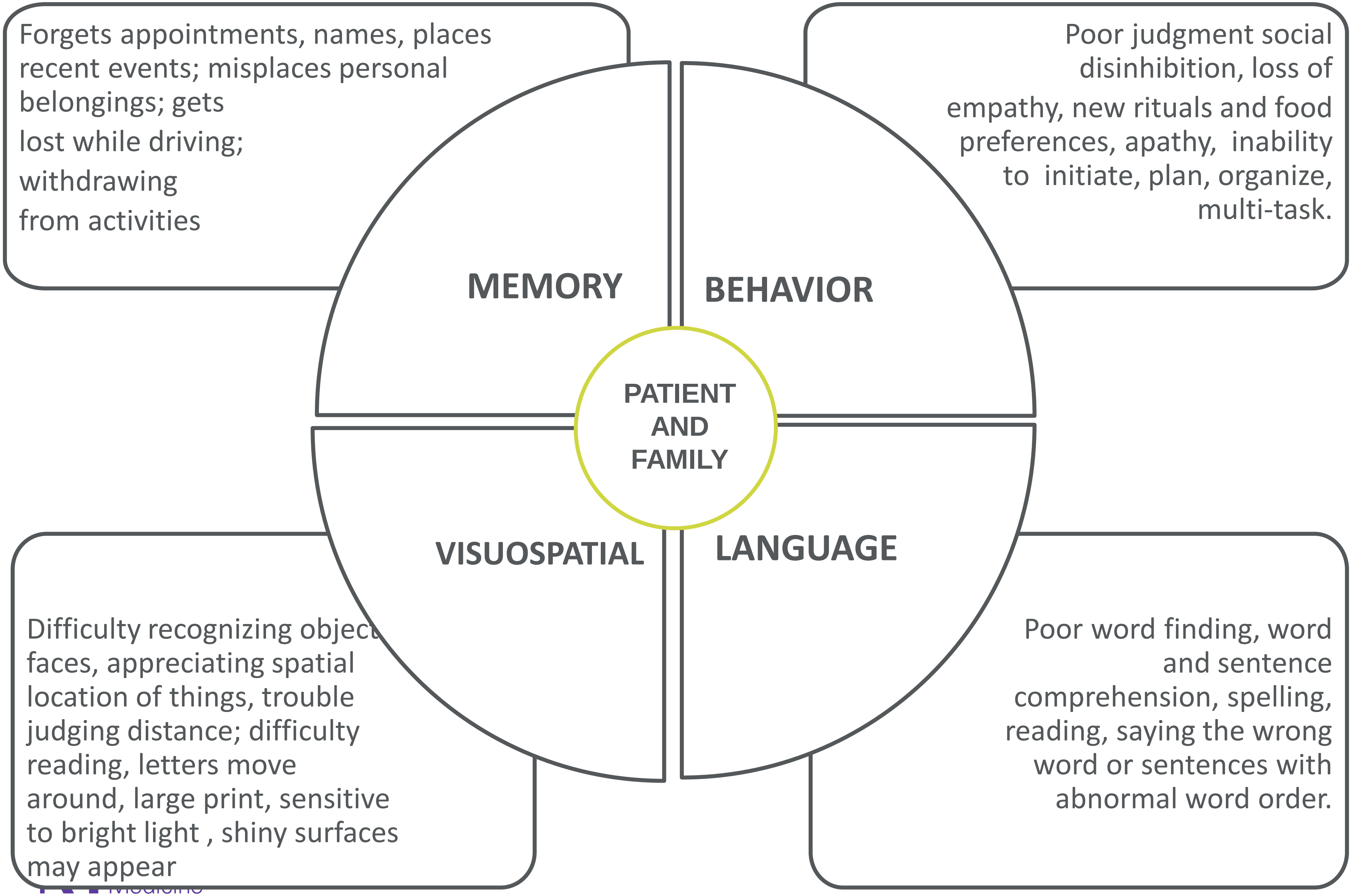
Motor Variant

- CBD, PSP, FTD-MND

Support and Care for Persons with FTD and Families: A Different Approach

- The FTD Pathway
- How is caring for someone living with FTD different than other forms of dementia?
- Care and support for persons living with FTD and their families: What is possible?
- Using technology to support persons living with FTD and their families

The CARE PATHWAY MODEL for Dementia



MEMORY

Forgets appointments, names, places recent events; misplaces personal belongings; gets lost while driving; withdrawing from activities

BEHAVIOR

Poor judgment social disinhibition, loss of empathy, new rituals and food preferences, apathy, inability to initiate, plan, organize, multi-task.

PATIENT AND FAMILY

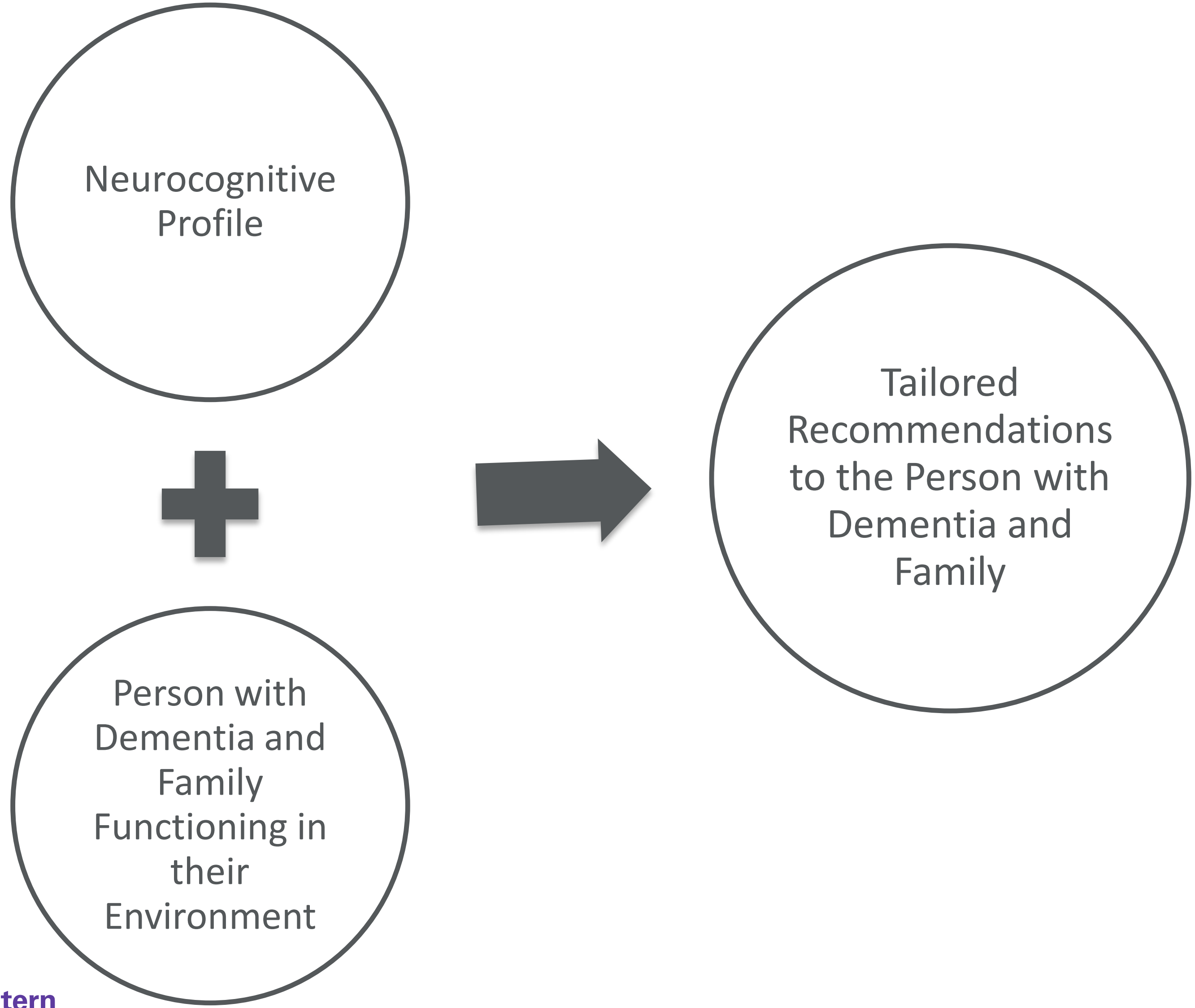
VISUOSPATIAL

Difficulty recognizing object faces, appreciating spatial location of things, trouble judging distance; difficulty reading, letters move around, large print, sensitive to bright light , shiny surfaces may appear

LANGUAGE

Poor word finding, word and sentence comprehension, spelling, reading, saying the wrong word or sentences with abnormal word order.

The CARE PATHWAY MODEL for Dementia



Neurocognitive Profile

Person with Dementia and Family Functioning in their Environment

Tailored Recommendations to the Person with Dementia and Family

Morhardt, D., Weintraub, S., Khayum, B, et al., (2015).

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FTD does not follow the same pathway as other forms of dementia

FTD: Different Pathway – Different Interventions

- FTD is not associated with memory problems

- Person & family centered approaches need to include assessment of:
  - Cognitive and functional abilities
  - Interests and preferences
  - Decision making capacity
  - Components of family functioning
  - Developmental phase
  - Illness time phase

How does FTD affect:

The person who has it?

Family Relationships

What Helps?

Different Caregiving Experience

- FTD symptoms/behaviors – loss of emotion, apathy - disruptive to relational connection and communication
- Higher levels of depression, stress and burden.
- Younger age of onset
- Difficulty obtaining diagnosis

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Care and Support for Persons Living with FTD: What is Possible?

Non-medication approaches

- Family education and understanding of symptoms
- Care partner approach, attitude and expectations
- Care tailored to the person’s preferences, abilities and strengths

Communication Strategies

- Adjust expectations regarding how the person expresses themselves. It's ok if not speaking grammatically. Do not over correct or interrupt.

- In some instances try electronic communication alternatives.

- Verbal or visual cues for word finding or naming difficulties. Ask for gesture or demonstrations.

- If someone has difficulty understanding you simplify your communication. Use shorter sentences, slow down, emphasize key words. Take your time.

Seek Early Speech Pathology Input

Behavior Strategies

- Apathy
  - Accept that you may need to initiate and carry conversation
  - Use positive motivation and feedback
  - Redirect / supervise to keep on task
  - Look for signs of self-neglect, safety risk
  - Capitalize on remaining strengths, abilities, preferences

- Disinhibition & Impulsivity
  - Use firm but kind limit setting to re-direct
  - Use humor
  - Use companion cards
  - Avoid rationalizing
  - Remain calm
  - Empathize with their frustration
  - Ask how you can help
  - Avoid known triggers

What do family care partners of persons living with FTD suggest?

- *Don’t try to reason with your loved one if he or she is unable to do so.*
- *Choose your battles*
- *Modify your own expectations rather than expecting the person to be the way he or she was before…acceptance is slow but is the key to setting you free.*
- *If the person with FTD has impulse control difficulties, don’t set them up to fail by presenting them with environmental cues that elicit problems.*
- *If the person is frustrated by communication difficulties, avoid placing them in situations in which communication is heavily relied upon, such as phone calls, group day programs, or large social gatherings.*

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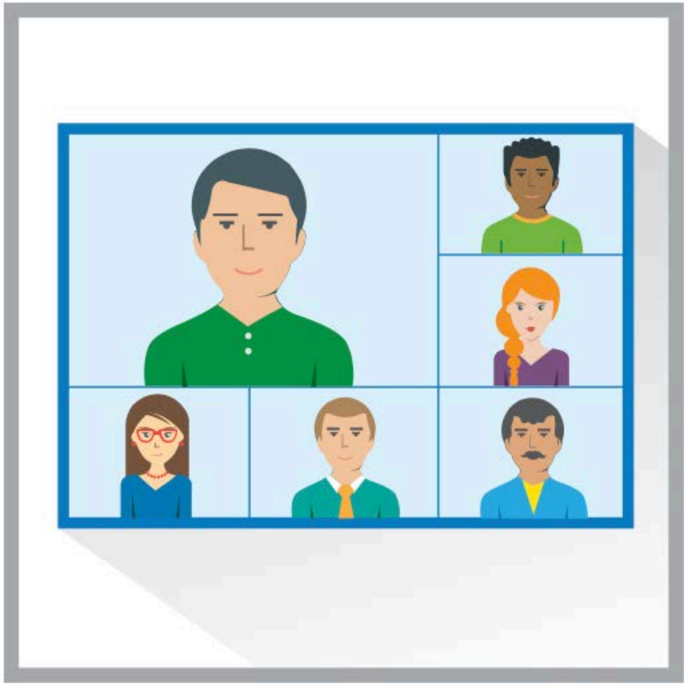
Not every strategy will work for every person living with FTD and not every strategy will work every time.

Using Technology

Internet-based Videoconferencing, Support/Chat Forums/Groups



YAHOO!
GROUPS

communication BRIDGE

Telemedicine randomized controlled trial for adults with mild PPA evaluating whether a person-centered treatment maximizes functional communication participation better than a dose-matched control treatment.

Who?

- Individuals with a diagnosis of Primary Progressive Aphasia (PPA) and their Communication Partners

Why?

- To better understand the effects of speech language therapy on communication abilities for individuals with PPA.

Where?

- All components of the study take place remotely via video-conferencing.

Key Study components:

- 5 Evaluations with a licensed speech language therapist
- 15 Therapy Sessions with a licensed speech language therapist over the course of 1 year
- Exercises through customized Web-Application

communicationbridge@northwestern.edu | 312-503-4012

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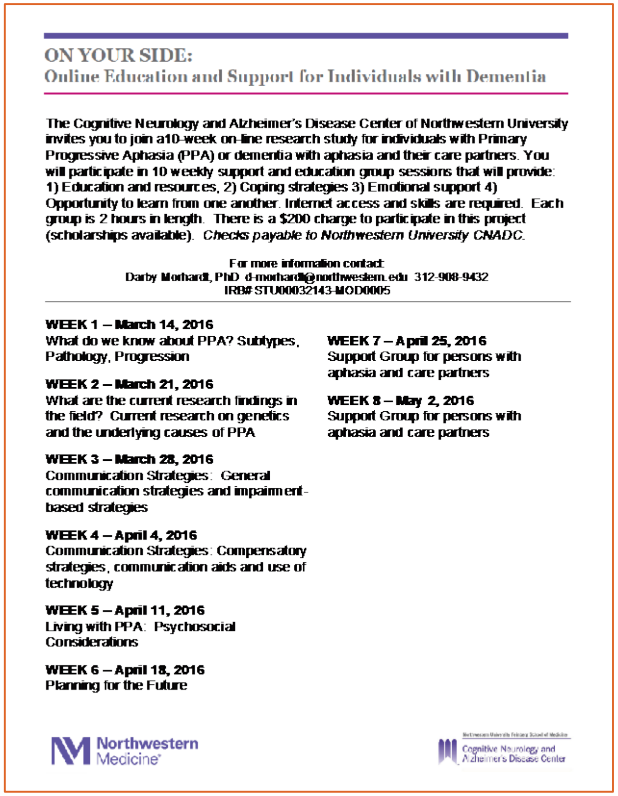
On Your Side: Online Support and Education for Individuals with PPA and Their Families

- Feeling sense of belonging through shared experience
- Sharing compensatory strategies
- Connecting over changes/loss
- Expressing resilience/empowerment



ON YOUR SIDE:

Online Education and Support for Individuals with Dementia

The Cognitive Neurology and Alzheimer's Disease Center of Northwestern University invites you to join a10-week on-line research study for individuals with Primary Progressive Aphasia (PPA) or dementia with aphasia and their care partners. You will participate in 10 weekly support and education group sessions that will provide: 1) Education and resources, 2) Coping strategies 3) Emotional support 4) Opportunity to learn from one another. Internet access and skills are required. Each group is 2 hours in length. There is a $200 charge to participate in this project (scholarships available). *Checks payable to Northwestern University CNADC.*

For more information contact:
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IRB# STU00032143-MOD0005

WEEK 1 – March 14, 2016
What do we know about PPA? Subtypes, Pathology, Progression

WEEK 2 – March 21, 2016
What are the current research findings in the field? Current research on genetics and the underlying causes of PPA

WEEK 3 – March 28, 2016
Communication Strategies: General communication strategies and impairment-based strategies

WEEK 4 – April 4, 2016
Communication Strategies: Compensatory strategies, communication aids and use of technology

WEEK 5 – April 11, 2016
Living with PPA: Psychosocial Considerations

WEEK 6 – April 18, 2016
Planning for the Future

WEEK 7 – April 25, 2016
Support Group for persons with aphasia and care partners

WEEK 8 – May 2, 2016
Support Group for persons with aphasia and care partners

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Northwestern University Feinberg School of Medicine
Cognitive Neurology and Alzheimer's Disease Center

Experiences of FTD Support Group Participants

- Sense of belonging in spite of differences in symptoms and backgrounds.
- Ability to empathize with each other's challenges with the limitations of the health care and social service systems.
- Taking the effort to try to create something positive.
- The relief to be able to share, give and receive support from others and have the ongoing professional support and information.
- A sense of hope.