

Support Groups for Persons with Early Stage Alzheimer's or Dementia

Melora Jackson, MS, CMHT

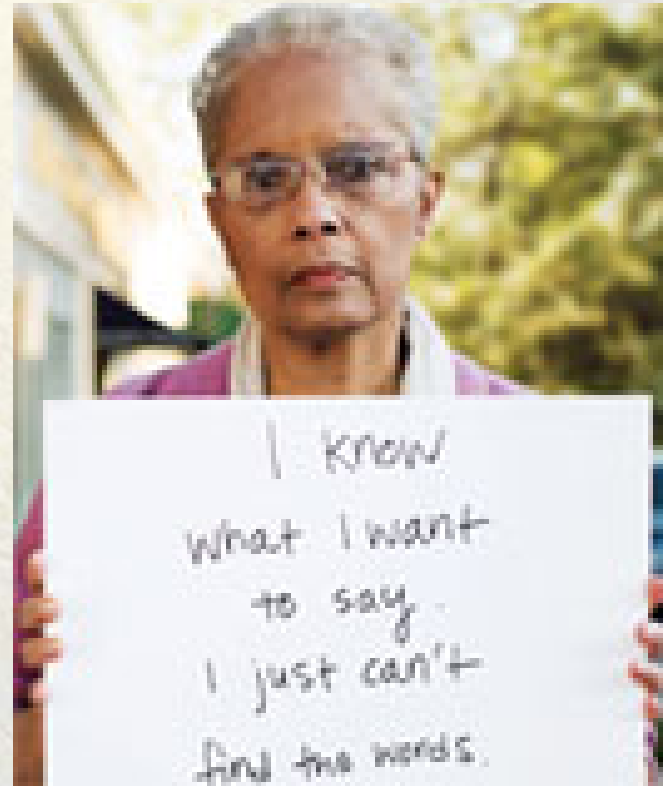


Support Needs

- Emotional
- Strategic planning
- Social
- Maintaining/maximizing abilities
- Preserving choice

Emotional Needs

- Grief
- Self-esteem
- Sense of control
- Dignity
- Fear
- Depression



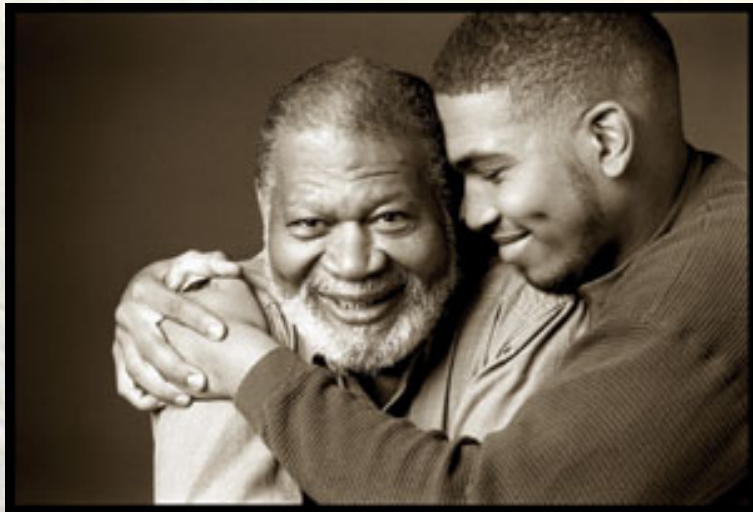
Planning Needs

- Legal & financial arrangements
- Care preferences



Corbis

Social Needs



- Communication with others
- Relationship roles & dynamics
- Social stimulation
- Sense of belonging
- Reduce stigma
- Reduce isolation

Preserving Abilities

- Maintaining functioning
- Maximizing remaining abilities
- Preserving lifestyle and preferences

Benefits of Support Groups

- Work on developmental tasks
- Grief work
- Decision-making
- Taking control of self
- Learn coping strategies
- Social support
- Information
- Hope



Limitations

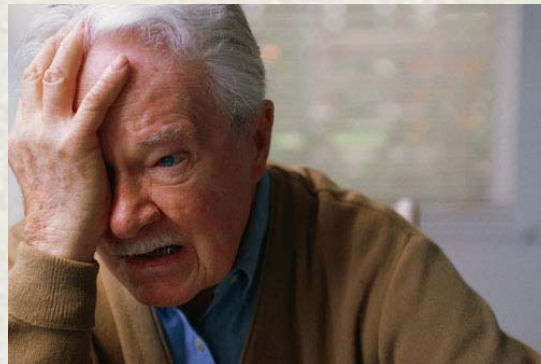
- Support groups don't work for those are not interested
- Not a replacement for therapy or counseling
- Not a social gathering, though there is some socializing
- Not a formal class being taught, though information is given

Developmental Tasks

- Erikson – ego development
 - integrity vs. despair (65+)
 - generativity vs. self-absorption or stagnation (35 – 55 or 65)
 - So what happens if you get AD and you're in this stage?
- Butler – life review
 - Putting one's house in order
 - Life review at a younger age?

Grief

- Stages of grief – shorter time to go through process than family/friends
- What's it like to grieve the loss of one's own self vs. loss of someone else
- Facilitation of the grief process



Decision-Making

- Making decisions in the midst of grief
- Considerations for making decisions
 - Who is able to make decisions
 - Who is allowed to make the decisions
 - Who is affected by the decisions



Control Over Care

- How much control can the person exercise
- Does the individual have as much control as preferred
- What does control mean to the person with AD/dementia
- Family system – helpful or challenge?

Elements of a Successful Group

- Facilitator training & qualifications
- Time – length, frequency, day & time
- Topics
- Format
- Screening participants
- Balance of education & social support

Topics

- Financial & legal planning
- Driving
- Telling others about Diagnosis
- Safety
- Grief work – the life not planned on
- Spiritual needs
- Planning
- Disaster preparedness
- Coping strategies

Social Support

- **My Social Network Map**

Write in each box the names of the people you meet in the following categories—see example below.

- **An example of how to complete your network map:**

- I meet my friend Emily every week.
- I meet my sister Gail every day.
- I meet Paul at the book club once a month.
- I see Tony when I volunteer at the library every other week.

| | | Daily | Weekly or more often | Approx. every 2 weeks | Monthly or less often | Rarely |
|---------------|-----------------------------------|-------|----------------------|-----------------------|-----------------------|--------|
| MYSELF | Family | Gail | | | | |
| | Friends | | Emily | | | |
| | Neighbours | | | | | |
| | Activities where I met people | | | | Paul | |
| | Work or organizations I belong to | | | Tony | | |

In this example, Gail and Emily are much closer to **MYSELF** than Tony and Paul.

Planning for the Future

- Personal planning – activities/interests
- Checklists
- Medical profile & advance directives
- Legal & financial
- Who can/should help the person with planning

Facilitation

- Professionals vs. lay people – need a stronger skill set than relevant life experience
- Experience in group work
- Personal qualities
 - Empathy, patience, good communication skills
- Training
- Co-facilitator or assistant – define roles

Structure

- Open-ended vs. time-limited
- Six to eight members
- Age of participants/composition of membership
- Ground rules
- Screening participants for appropriateness
 - Cognitive ability/awareness
 - Attitude – whose idea is it for involvement
 - Behavior issues

Balancing

- Support
 - Time dedicated to open discussion
 - Facilitation vs. teaching
- Education
 - Have extra information and topics available
 - Flexibility with topical information

Evaluation

- Group as a whole
- Individual
- Frequency of evaluation
- Formal & informal evaluation



Models

- Higher structure – educational class
- Mutual Aid Model – Alz. Society of Canada
- Combination model

Resources

- Robyn Yale – San Francisco consultant/author
 - Books and training materials
- Lisa Snyder – UC San Diego Shiley-Marcus Alzheimer's Disease Research Center
 - Newsletter for people with dementia
 - Network for facilitators
- Alzheimer's Society of British Columbia
 - Share the Journey™
 - Booklet by people with AD

References

- 1. Yale, R. (1995) *Developing Support Groups for Individuals with Early Stage Alzheimer's Disease: Planning, Implementation and Evaluation*, Health Professions Press: Baltimore, MD.
- 2. Snyder L, Quayhagen MP, Shepherd S, Bower D. Supportive seminar groups: an intervention for early stage dementia patients. *Gerontologist*. 1995 Oct; 35(5):691-5.
- 3. Goldsilver PM, Gruneir MR. Early stage dementia group: an innovative model of support for individuals in the early stages of dementia. *Am J Alzheimers Dis Other Demen*. 2001 Mar-Apr;16(2):109-14.