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

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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
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 who 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.
<table>
<thead>
<tr>
<th>MYSELF</th>
<th>Daily</th>
<th>Weekly or more often</th>
<th>Approx. every 2 weeks</th>
<th>Monthly or less often</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>Gail</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>Emily</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighbours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities where I met people</td>
<td></td>
<td></td>
<td>Paul</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work or organizations I belong to</td>
<td></td>
<td></td>
<td>Tony</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

