QUALITY OF LIFE IN DEMENTIA

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PROGRESSIVE DEMENTIAS

After D. Knopman, 1999

LEWY BODIES
DEMENTIA WITH PARKINSONISM
“Without quality of life, quality of care doesn’t matter that much”

Anonymous
**MEANINGFUL ACTIVITIES**

- **ACTIVITIES OF DAILY LIVING (ADLs)**
  - Appropriate level of cueing, set up and assistance, controlled choices, promotion of functional independence, social occasion
- **PERSON-CENTERED CARE**
  - Lifestyle approach, music preferences, reminiscence, Eden Alternative
- **USE OF TECHNOLOGY**
  - Simulated Presence Therapy, Snoezelen
**CONTINUOUS ACTIVITIES**

- Activity programming or presence of others most of their waking hours
- Residents with all stages of dementia
  - Adjusted to dementia severity
  - Planned and unplanned activities
  - Involvement of all staff, family and volunteers

**ACTIVITY PROGRAMS**

<table>
<thead>
<tr>
<th>INDEPENDENCE</th>
<th>MILD</th>
<th>MODERATE</th>
<th>SEVERE</th>
<th>TERMINAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEMORY ENHANCEMENT PROGRAM</td>
<td>THE CLUB</td>
<td>NAMASTE CARE</td>
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</tbody>
</table>
MEMORY ENHANCEMENT PROGRAM

- Small group (<15) meeting daily
- Morning routine
- A variety of brain exercises
- Integration with other residents for physical exercises and selected programs

RESIDENTS APPROPRIATE FOR MEP

- Mild Cognitive Impairment
- Early Alzheimer’s disease
- Medical conditions causing memory loss
- Other medical, social conditions
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THE “INBETWEENER”

- Does not attend activity programs
- Isolated in room because it’s safe
- May be depressed
- Sits in the lobby
- Sits outside the dining room hours before the meal
- Can’t find their room
- Repeats and repeats and repeats

DAILY ROUTINE

- Meet & Greet
- Morning Ritual
- Exercise
- AM program
- Trivia
- Lunch
- Rest & relax
- Reminisce
- Sip & snack
- Afternoon delight
- Brain exercises
- Dinner
THE CLUB

- Usually on a dementia unit
- PHYSICAL ACTIVITIES
  - Improve mood, strength, sleep, tone
- COGNITIVE ACTIVITIES
  - Games, sorting, brain exercises, reminiscence
- CREATIVE ACTIVITIES
  - Drawing, singing, crafts, dance, music

ACTIVITY STAFF RESPONSIBILITY

- Lead the program
- Teach nursing assistant “how to”
- Recruit and train volunteers
- Develop/evaluate the daily routine
- Develop/evaluate the monthly calendar
- Evaluate/ revise as needed
  - Changes in residents interests
  - Seasonal changes
  - Keep it interesting & fun!
NURSING ASSISTANTS
RESPONSIBILITY

- Invite & accompany residents to “The Club”
- At least one is assigned to stay in the room
- Lead programs
- Assist with snacks
- Toilet/groom

ADMINISTRATOR & DEPARTMENT MANAGERS
RESPONSIBILITY

- Assist with transporting residents to “The Club”
- Leads programs
- Fills in when necessary
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DAILY ROUTINE

- Meet & Greet
- News & Views
- Physical Exercise
- Sit & Sip
- Morning Surprise
- Food Trivia
- March to Dine

- Afternoon Delight
- Fun & Games
- Chat & Chew
- Brain teasers
- Dinner
- Trivia
- Movie

NAMASTE CARE

- Presence of others – group room, carer always present (7 days/week, 5hrs/day)
- Comfortable environment – reclining chairs, bird sounds, relaxing music, lavender scent
- Individualized care – hand and foot massage, ADL as meaningful activities
- Easy to implement, no additional staffing

J. Simard: The End-of-Life Namaste Care Program for People with Dementia, Health Professions Press 2007
**PVS IN ALZHEIMER’S DISEASE**

- 12 patients unable to eat independently, respond to command, walk, incontinent
- 9.4 years history, 43 months institutionalization
- No agreement among three neurologists on any patient

**QUALITY OF LIFE CONSIDERATIONS**

- Patients almost never reach a persistent vegetative state
  - Need for sensory stimulation (Namaste)
- Optimal medical interventions
  - Establish goals of care
- Management of behavioral symptoms
  - Treat / eliminate depression
RESIDENTS SUITABLE FOR NAMASTE CARE

- Advanced Dementia
- Parkinson's disease, late stage
- Emphysema
- Hospice patients
- Terminally ill with other diagnosis
- Residents who are disruptive in activities
- Residents having a “bad” day/agitated
- Head injury
- Returning from a hospital stay
- Very old and very tired, sleeps most of the day

MORNING NAMASTE CARE

- Welcome to Namaste:
  - Each person is touched as they come into the room
  - A quilt or blanket is tucked around them
  - Extra pillows or towels used to position
  - Placed in a comfortable lounge chair
  - Assessed for pain
- Personal care:
  - Wash hands & apply lotion
  - Wash face and apply face cream
  - Shave men
  - Massage neck, arms
  - Hair brushed
MORNING NAMASTE CARE

- Activities
  - Talk about the day
  - Use bird sounds
  - Take scents to each person to remind them of the weather i.e. rain, grass, flowers, fir trees
- Give them a friend!
  - Large dogs, kittens, rabbits
  - As life-like as possible
  - Not “childish”

AFTERNOON NAMASTE CARE

- Videos, nature, music
- Individual reminiscence
- Foot washing and lotion
- Range of motion
- Shift staff change
- Residents who were napping come to program
- Family visits
- Room closes residents transported to dining room
- Paperwork completed
- Room cleaned and restocked
Meaningful Activities

Medical Issues

Psychiatric Symptoms

QOL

Comfort

Prolongation of life

Relief of suffering

A good death

Quality of life

Staying in control

Support for family and loved ones

POTENTIAL GOALS OF CARE

- Cure of disease
- Avoidance of premature death
- Maintenance of improvement in function
- Prolongation of life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for family and loved ones
### Multiple Goals of Care

- Multiple goals often apply simultaneously
- Goals are often contradictory
- Certain goals may take priority over others

### Goals of Care

<table>
<thead>
<tr>
<th>Medical</th>
<th>Individual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical facts</td>
<td>Values</td>
</tr>
<tr>
<td>Burdens/benefits of therapy</td>
<td>Priorities and utilities</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Culture</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>Life experience</td>
</tr>
</tbody>
</table>
STRATEGY FOR SETTINGS GOALS

- Agree on as many goals as possible and work out treatment plan
- Focus on short-term goals and plans
- Use time-limited therapeutic trials with agreed-on end points
- Review with any change in health status, illness progression, and setting of care

ADVANCE MEDICAL PLANNING

<table>
<thead>
<tr>
<th>LEVEL OF CARE</th>
<th>LIFE PROLONGATION</th>
<th>MAINTENANCE OF FUNCTION</th>
<th>MAXIMAL COMFORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTENSIVE CARE</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>COMPREHENSIVE CARE</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>BASIC CARE</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>PALLIATIVE CARE</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>COMFORT CARE</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>ONLY CARE</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
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Gillick et al, JAGS 47:227-230,1999
7-STEP PROTOCOL TO NEGOTIATE GOALS OF CARE

1. Create the right setting
2. Determine what the patient and family know
3. Explore what they are expecting or hoping for
4. Suggest realistic goals
5. Respond emphatically
6. Make a plan and follow-through
7. Review and revise periodically, as appropriate

From The EPEC Project, AMA

MEDICAL INTERVENTIONS

- CPR - < 2% DISCHARGED ALIVE
  (Applebaum et al., JAGS 38, 197, 1990)
- TRANSFER TO A HOSPITAL
  - HIGHER MORTALITY AT TWO MONTHS THAN THOSE TREATED AT NH (Fried et al., JAGS 45, 302, 1997)
  - >50% MORTALITY RATE AT 6 MONTHS AFTER HOSPITALIZATION FOR PNEUMONIA OR HIP FRACTURE (Morrison and Siu, JAMA 284,47,2000)
FACTORS CONTRIBUTING TO DEVELOPMENT OF INTERCURRENT INFECTIONS

- Changes in immune function
- Difficulties in diagnosing infections
- Incontinence
- Decreased mobility
- Aspiration

USE OF MERRY WALKER IN ALZHEIMER’S DISEASE

- Improved mobility
- Decreased daytime sleep
- Improved mood
- Increased engagement
- No injuries
INTERCURRENT INFECTIONS

- Limited effectiveness of antibiotics
- Adverse effects of antibiotics
  - GI symptom
  - Allergy
  - C. difficile
- Comfort can be maintained without use of antibiotics (analgesics, antpyretics, oxygen)

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<th>MILD</th>
<th>MODERATE</th>
<th>SEVERE</th>
<th>TERMINAL</th>
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</thead>
<tbody>
<tr>
<td>WEIGHT LOSS</td>
<td>APRAXIA</td>
<td>SWALLOWING DIFFICULTIES</td>
<td>UNABLE TO OPEN MOUTH</td>
</tr>
<tr>
<td>INDEPENDENCE</td>
<td>CHEWING DIFFICULTIES</td>
<td>FOOD REFUSAL</td>
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PROGRESSION OF DEMENTIA
DISADVANTAGES OF TUBE FEEDING

- Discomfort, restraints
- Lack of taste of food
- Lack of contact with caregivers
- Complications
  - diarrhea and cramps
  - nausea, vomiting, abdominal distention
  - tubal obstruction and migration
  - infection and leakage of stoma

PREVENTION OF TUBE FEEDING

- Palliative philosophy of care
- Early discussion of advance directives
- Continuous effort to feed patients by natural means
- Maintaining quality of life
- Continuous communication with patients families
ADVANTAGES OF TERMINAL DEHYDRATION

- Decreased secretions
  - Upper respiratory tract – cough, suctioning
  - Digestive tract – diarrhea, vomiting
- Less urine formation – decubiti
- Analgesia – increased secretion of endorphins (co-secretion with vasopressin), increased level in the brain (Yakovleva et al, Neurobiol Aging 28,1700,2007)

MEANINGFUL ACTIVITIES

MEDICAL ISSUES

PSYCHIATRIC SYMPTOMS

QOL

COMFORT

DEPRESSION

MOTOR ACTIVITY
### PAINAD Scale

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td>Normal</td>
<td>Occasional labored breathing</td>
<td>Noisy labored breathing</td>
</tr>
<tr>
<td>Independent of</td>
<td></td>
<td>Short period of hyperventilation</td>
<td>Long period of</td>
</tr>
<tr>
<td>vocalization</td>
<td></td>
<td></td>
<td>hyperventilation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cheyne-stokes respirations</td>
</tr>
<tr>
<td>Negative</td>
<td>None</td>
<td>Occasional moan or groan</td>
<td>Repeated troubled</td>
</tr>
<tr>
<td>Vocalization</td>
<td></td>
<td>Low level speech with a negative or</td>
<td>calling out</td>
</tr>
<tr>
<td></td>
<td></td>
<td>disappointing quality</td>
<td>Loud moaning or</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>groaning</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Crying</td>
</tr>
<tr>
<td>Facial</td>
<td>Smiling, or</td>
<td>Sad, Frightened, Frown</td>
<td>Facial grimacing</td>
</tr>
<tr>
<td>expression</td>
<td>Inexpressive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body Language</td>
<td>Relaxed</td>
<td>Tense, distressed, pacing, Fidgeting</td>
<td>Rigid, Fists drooped,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Knees pull up. Pulling</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>or pushing away.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Striking out</td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch</td>
<td>Unable to console,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>distract or reassure</td>
</tr>
</tbody>
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Warden et al. JAMDA 4, 9-15, 2003

### Behaviors with negative impact on QOL of patients/residents

- **AGITATION/APATHY**
  - While solitary
- **RESISTIVENESS TO CARE**
  - While interacting
FACTORS LEADING TO ABUSIVE BEHAVIOR IN RESIDENTS WITH DEMENTIA

- Understanding
- Hallucinations
- Delusions
- Depression

Resistiveness to care

- Verbal abuse
- Physical abuse

Partial correlations controlled for resistiveness to care

** p<.001, *p<.005

RISK FACTORS FOR PHYSICAL ABUSE

- Both lack of understanding and depression
- Only depression
- Only lack of understanding
- No risk factors

- 70%
- 19%
- 6%
- 4%
**CAUSES OF BEHAVIORS**

- **Apathy/Agitation** = lack of meaningful activities
- **Abusive behavior**
  - Escalation of resistiveness to care = need for care modification
  - Depression or delusions = need for effective treatment

**SUPPORT OF CAREGIVERS**

- 36-hour day
- Consequences of caregiving:
  - Depression
  - Physical diseases
- Interventions
  - Individual counseling
  - Support groups
  - Respite
"People do not consist of memory alone. They have feeling, will, sensibility, moral being. It is here that you may touch them, and see a profound change."

A. Luria