

DEMENTIA HAND-IN-HAND PROGRAM

Home Health VNA
Merrimack Valley Hospice
HomeCare, Inc.



The Leaders In Home Health and Hospice Care

Definition


Impaired intellectual
and cognitive
functioning

- Loss of memory
- Impaired ability to learn new information or to recall information
- Deterioration of judgment, planning, & organizing
- Decline in emotional control or motivation
- Change in social behavior
- Normal consciousness

Progressive
Brain
Dysfunction

Death

Demographics of Dementia

- ▶ 4.5 million Americans are affected
 - ▶ By 2050, 16 million will be affected
 - ▶ 4th leading cause of death among older adults
 - ▶ Average life expectancy is 8 – 10 years following diagnosis
 - ▶ 7/10 live at home and are cared for by family/friends
 - ▶ 75% of patients in LTC settings by late stage
 - ▶ Significant level of stress, depression, and grief are experienced by caregivers
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Criteria for Dementia: DSM IV

- ▶ **Memory Impairment**
- ▶ **One or more of below**
 - Aphasia
 - Apraxia
 - Agnosia
 - Disturbances in executive functioning

Mild Dementia



- Short-term memory
- Personality Change
- IADs (shopping, driving, etc)
- Loss of insight into problem areas

Moderate Dementia



- Short and Long term Memory
- Not able to organize and structure day
- Decline in gross and fine motor skills
- Activities of Daily Living
- Withdrawal
- Language skills decline
- Perseveration
- Personality changes and/or delusions, hallucinations

Severe Dementia



- Memory Loss
- Loss of recognition of family members
- ADLs (transferring, continence, etc)
- Further decline in cognition to total loss of language skills
- Weight loss and decline in appetite
- Altered motor skills
- Behavioral changes

End Stage Dementia



- Few Intelligible Words
- Bedbound
- Progressive Dysphagia
- Behavioral Changes

Subtypes

- ▶ **Alzheimer's disease** 35%
- ▶ **Mixed** 15%
 - Alzheimer's disease & Vascular
- ▶ **Lewy body dementia** 15%
- ▶ **Vascular dementia** 10%
- ▶ **Frontotemporal dementia** 5%
 - Pick's disease

Prognostic Systems

It's about Life Expectancy

▶ FAST

- Functional assessment staging
- NHPCO: FAST 7C
 - A: Fewer than 6 intelligent words
 - Inability to walk, dress, bathe
 - Incontinence
 - Requires assistance with ambulation
- Dementia-related comorbidity
- Inability to maintain fluid/caloric intake to sustain life
- Median survival: 6.9 mos.

Symptom Control

- ▶ Pain
- ▶ Behavioral
- ▶ Psychological
- ▶ Mood disorders
- ▶ Apathy
- ▶ Psychosis
- ▶ Agitation

Behavioral and Psychological Symptoms in Dementia

- ▶ **Behavioral dyscontrol**
 - Euphoria
 - Disinhibition
 - Aberrant motor behavior
 - Sleep and appetite disturbances
- ▶ **Psychological dyscontrol**
 - Mood disorders
 - Depression, anxiety, apathy
 - Psychosis and delusions
 - Visual and auditory hallucinations
 - Agitation
 - Aggression and irritability

Mood Disorders

- ▶ **Depression is common**
 - Standardized instruments
 - Mild to moderate: validated
 - Moderate to severe: less reliable
 - Look for changes in
 - Mood
 - Behavior
 - Sleep
 - Cognition
 - Functioning
 - Appetite and weight loss
 - Social withdrawal
 - Apathy
- ▶ **Empirical trial of antidepressant**

Apathy

- ▶ **Prevalence greater than 50%**
- ▶ **Early in disease course**
- ▶ **Loss of motivation**
 - Differs from depression
 - No symptoms of altered mood
 - Antidepressants: no role
 - Psychostimulants and cholinergic therapy
- ▶ **Look for**
 - Diminished initiation
 - Lack of insight
 - Blunted emotions
 - Decreasing social engagement

Psychosis

- ▶ **Delusions and hallucinations**
 - Delusions up to 30%
 - Hallucinations up to 20%
 - Lewy body dementia:70%
- ▶ **Risk factors**
 - Severity of dementia
 - African American ethnicity
 - Extrapiramidal symptoms (EPS)
 - Sensory impairment

Agitation

- ▶ Up to 50% with agitation or irritability
- ▶ Imprecise term
 - Delirium
 - Depression
 - Terminal symptoms
 - Underlying dementia

Causes Contributing to Agitation

- ▶ **Physical symptoms**
 - Pain
 - Sleep disturbance
 - Sensory loss (vision, hearing)
- ▶ **Medical illness**
 - Delirium
 - Constipation/fecal impaction
 - Urinary retention
 - Seizure disorder
- ▶ **Medication/substance**
 - Digoxin
 - Theophylline
 - Ritalin
 - Antipsychotic
 - Benzodiazepine
 - caffeine
- ▶ **Unmet Needs**
 - Hunger
 - Social Isolation
- ▶ **Environment**
 - Unfamiliar surroundings
 - Overstimulation
 - Understimulation
- ▶ **Psychological symptoms**
 - Depression
 - Anxiety
 - Psychosis

Person-Centered Care

- ▶ Philosophy of care that recognizes and honors the value of the person regardless of the severity of the cognitive impairment
- ▶ Recognizes the emotional and spiritual needs of the person with dementia
 - Love
 - Comfort
 - Identity
 - Attachment
 - Inclusion

What is Spirituality?

“Spirituality is about the core meaning of connectedness...the essential dimension that brings meaning to life.” Elizabeth B MacKinlay

Whole Person Care

- A holistic approach is used to define spirituality in caring for persons with dementia
- Essentially caring for the “spirit” as the essence of good care.
- Addresses people of no particular faith and people with a particular faith tradition.
- Spirituality is the response of a person’s inner most being that influences their sense of meaning, belonging and purpose.

Role of Spiritual Care

- Assessing mind, body, and spirit; engaging the person in a meaningful way.
- Formulate lived events to construct meaning and purpose.
- Utilize relevant symbols that affirm a persons belief system.
- Foster a sense of belonging by valuing the “inner -being” vs their “diminished- being”

Inner-most being

Understanding “spirituality” as inner-most being encourages us to want to connect to a person



If art, music or nature have been the central source of meaning then they will continue make meaning and purpose



“Religion” or “Faith Tradition” is a piece of ones inner-most being, not the entirety of their being.



Rituals and symbols of a particular faith tradition can continue to create sense of belonging

Memory Impaired



Affirmation vs Correction

Problem– correction causes anxiety and “shuts-down” or “agitates”

Non-sensical Babble; can't be understood or answer questions.

Repetitive phrases/questions

Frustrations arise between person with dementia and caregiver; how do we “understand” them?

Intervention–Affirmation encourages participation and feeling safe

Make eye contact and provide affirmation with smile, nodding and verbal understanding.

Answer questions each time as if the first time.

Interpret “mood” and respond to ie: if showing sadness affirm it and provide assurance

Reality vs Intuition

Memory loss
impairs reality

- Making sense of their environment becomes a challenge
- Caregiver focused on Here and now reality

Relies on
Intuition

- Backwards development vs learning
- Takes cues from senses and environment to feel safe

Enter their
reality

- Become intuitive to where they are
- Create environment that conveys belonging, safety,

Challenges for EOL work

Reconciliation

- Forgiveness
- Acceptance

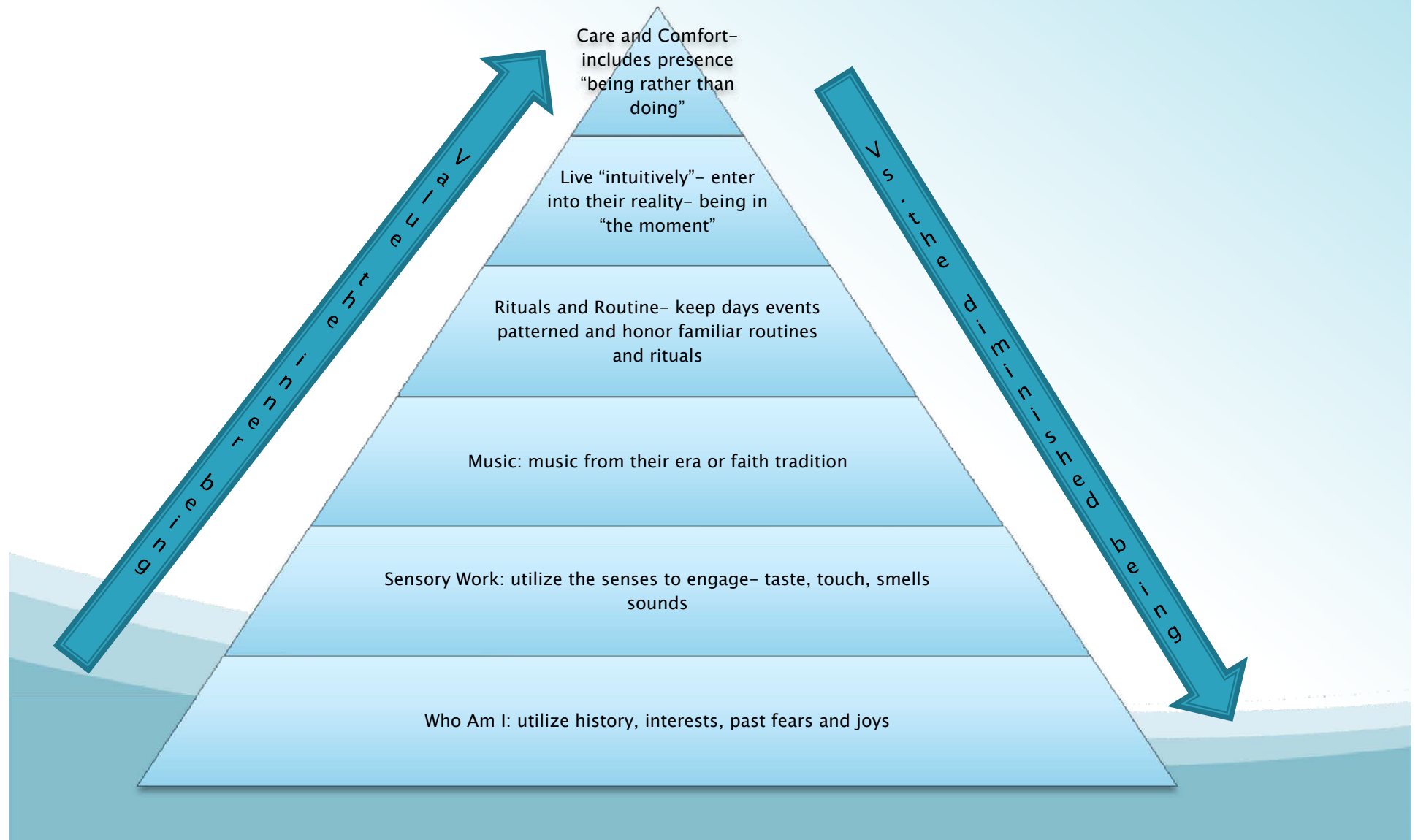
“Invisible”

- Legacy Work –creating memory book
- Hand in Hand– utilizing expressive interventions to maximize

Caregiver Fatigue

- Accepting help
- Family, hospice, volunteers

Making it Work



Anticipatory Grief

“Anticipatory grief is the phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future.”
Therese Rando

Life review

Education on death and dying process

Active listening

Explore ways of making meaning from the experience

Verbalization of anticipated loss

Completing unfinished Business

Family members response to Anticipatory Grief



“I so appreciate you looking out for my mom and keeping me updated as time goes on. It's sooooo difficult to see her in this condition, we've always been so close, I can only stay for a short time on a Sunday, it just tears me up too much, I feel blessed that at least she's physically there for us but it's just so hard to watch.

Family member of patient on Hand In Hand Program.

Early Stage Psychosocial Interventions

For Patient

- Provide daily structure & routine.
- Preserve and empower functional Independence & control
- Provide specific & clear instructions
- Understand that what works well one day may not the next day.
- Provide positive unconditional praise/reinforcement to the individual

For Caregiver

- ▶ Assess for grief/loss
- ▶ Assessing impact of diagnosis on relationship w/significant other or caregiver.
- ▶ Review management of daily tasks (ie bill paying, driving, role change, etc).
- ▶ Supporting caregiver in relating and maintaining relationship w/patient.
- ▶ Advance care planning (ie. HCP, DNR, Nutrition, Financial/Legal).
- ▶ Community Referrals
- ▶ Educate on disease progression

Moderate Stage Psychosocial Interventions

For Patient

- ▶ **Increased need for supervision**
 - Home w/caregiver or agency care, Assisted Living, SNF placement
- ▶ **Environmental modification.**
- ▶ **Non –pharmacological Interventions**
 - **Wander programs / bracelets.**
 - MedicAlert®, Safe Return® and/or Project Lifesaver network
 - **Enhance communication skills to decrease agitation/confrontation.**

For Caregiver

- ▶ **Assess, Educate and Empower.**
- ▶ **Assess need for increased home care supports or skilled setting.**
- ▶ **Maintain caregiver's connection with social relationships.**
- ▶ **Assessing and reinforcing caregivers emotional/psychological well being.**
- ▶ **Enhance caregivers communication skills with patient**
- ▶ **Modification of daily tasks and activities to meet changing cognitive capacities**
- ▶ **Referrals to community and financial resources**
- ▶ **Education on disease progression & what to expect over next several months.**
 - Opportunity to revisit advanced directives and LTC planning.

Late Stage Psychosocial Interventions

For Patient

- ▶ **Provide constant direction/instructions when engaging patient such as introducing self, telling the patient what you are going to do before it happens & continuing this line of communication from start til end.**
- ▶ **Use of comforting touch and non verbal communication.**
 - 93% of communication happens non -verbally
 - Expression (tone in one's language) - accounts for approx. 35% of the message.
 - Body language - accounts for approximately 58 % of the message (power of a smile!)
- ▶ **Use of sensory interventions to "engage" patient (music, tactile objects, scent, images, sounds, etc.)**
- ▶ **Create a pleasant, sensory soothing environment.**

For Caregiver

- ▶ **Anticipatory grief & supportive counseling**
 - Encourage maintenance of caregiver relationship. (ie. Watch for those disconnecting)
- ▶ **Bolster formal and informal support structure (family, friends, church community, support groups)**
- ▶ **Reinforce comfort goals.**
- ▶ **Educate on end stage dementia disease progression and dying process**
- ▶ **Provide emotional support and listening presence and seek to find meaning making in the care-giving process**
- ▶ **Address EOL practical issues such as funeral planning or financial needs concerns.**

Affirm vs correct

Never condescend
instead encourage

never reason
instead divert

Communication Strategies

Never "you can't"
instead "Do what
you can"

never lecture
instead re-assure

never "I told you"
instead repeat

Difficult – Challenging Behaviors

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"It's ok Joe, forget it!"

Agitation

Hallucinations

Wandering

Screaming & or Yelling Out

Repetitive Actions

Wanting to go home

Sexualized Behaviors

Causes Contributing to Agitation

- ▶ **Physical symptoms**
 - Pain
 - Sleep disturbance
 - Sensory loss (vision, hearing)
- ▶ **Medical illness**
 - Delirium
 - Constipation/fecal impaction
 - Urinary retention
 - Seizure disorder
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- ▶ **Unmet Needs**
 - Hunger
 - Social Isolation
- ▶ **Environment**
 - Unfamiliar surroundings
 - Overstimulation
 - Understimulation
- ▶ **Psychological symptoms**
 - Depression
 - Anxiety
 - Psychosis



Advanced Care Planning

DNR

Artificial Nutrition / Hydration

Future Hospitalization

Ventilation

Living Wills

HCP / DPOA

Financial/Estate Planning

Hand In Hand techniques to meet unique needs of patients with dementia:

▶ Story telling:

- Create the right scene – eliminate background noise
- Choose pictures carefully
- Learn questioning techniques
- Be persistent
- Integrate music
- “Go with the flow”

Techniques (continued);

▶ Music Therapy

- Music association
- Select music from patient younger years (18–25)
- Agitation management – playing, dancing, exercise may decrease agitation
- Emotional closeness – singing is associated with early life safety and security

Techniques (continued):


▶ Art therapy

- Keep it simple
- Evoke memories
- Play it safe – use materials that are harmless if swallowed
- Stimulating material – bright colors, cardboard boxes, yarn, old photo albums
- Comfortable setting


Techniques (continued):

- ▶ **Tactile stimulation: contributes to a feeling of trust and confirmation. Include touch, sight, hearing, smell and taste.**
 - Massage
 - Aroma therapy and pleasant, routine smells (spices, foods, outdoors)
 - Textures
 - Virtual environments

Frequently used adjuncts/supplies continued:

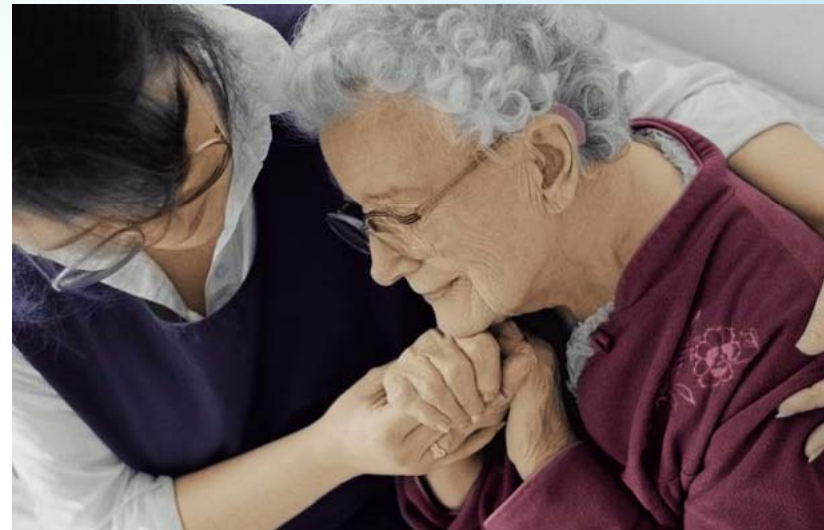
- ▶ Trivia for seniors handbook
 - ▶ Mardi Gras beads, old jewelry, bag of rubber bracelets
 - ▶ CD player/radio, tapes, CDs
 - ▶ Matchbox cars in a tin
 - ▶ Fabrics
 - ▶ Cards, dominos, cribbage
- 

Frequently used adjuncts/supplies:

- ▶ Picture book, calendars, “themed” activity sets
 - ▶ Instruments: tambourines, maracas, percussion blocks, washboard
 - ▶ Craft supplies: stickers, markers, paint and brush sets
 - ▶ Wooden puzzles
 - ▶ Bubbles
- 

Case Study: Maria

- ▶ Maria is an 89yo widowed female pt admitted to hospice with a medical diagnosis of Alzheimer's. She is living in a Long Term Care Facility.
- ▶ Maria presents as disoriented to time and place and is often agitated which is exhibited in calling out loudly, disturbing other residents.
- ▶ Pt is wheelchair/bed bound and dependent for all ADL's. Can use hands to hold objects. Will hold cup and drink but does not hold spoon/fork well.
- ▶ Pt is Catholic and is of Italian decent. Her two son's describe her as being a devoted mother who loved to cook and care for them. Sons report she does not recognize them now.
- ▶ Pt can engage with eye contact and phrases such as "I love you."
- ▶ Traditional medications for agitation have not reduced agitation/calling out to comfortable level .



Who I am...

My name is: Maria

I liked to be called: Maria often responds to being called “mama”

I was born in: Methuen MA and was very connected to the “Italian” section and its culture.

Important people: Two sons are devoted: Tony and Frank. Frank admits being with “mom” is hard for him.

I like to be remembered for: being the “Cake Lady” at bingo. Maria made special cakes for weekly bingo.

I like to reminisce about: Maria seems to respond to stories about holiday cooking. She responds with chatter or smiles.

My work Life: Maria was a house wife who raised her two son’s while her husband worked.

Things that bring me peace and solace: Was devoted to her faith as a Catholic. Enjoyed music from the 1940’s and 50’s era.

Favorite TV shows or movies: Did not watch much television. Unaware of what’s on TV but enjoyed the older music shows like Lawrence Welk.

Touch Preference: Likes to hold hands. Maria used to love a manicure and nails polished and she loves to have her head massaged.

Favorite Foods or Beverages: Italian foods and coffer (Maria is on puree/thickened diet). She also loves chocolate!

Favorite smells: Maria, as a cook loved the smell of cooking spices and herbs.


Sleeping habits: Maria has long spells of agitation and calling out then takes brief “naps” throughout day.

Things I dislike: Sudden approaches, lying flat on back.

What else you should know: Maria loved to crochet and made afghans for all her family and friends. She also prided herself on her “nice” appearance , always dressed neatly and with accessories.



Hospice referral

- ▶ Fewer than 10% of advanced dementia patients die with hospice services
 - ▶ Patients enrolled in hospice received regular treatment of pain
 - ▶ More likely to die in place of choice
 - ▶ Care givers were more likely to be satisfied with care
- 

Hospice Staff Roles in Dementia Care

- ▶ Each team member provides unique aspects of palliative care for the patient
 - Comfort
 - Quality of life
 - Dignity/respect
 - milieu
- ▶ Understanding role improves competence and job satisfaction

Hospice in Dementia Care

- ▶ Hospice care is an important benefit for the person with advanced dementia
- ▶ Hand in Hand is a program designed to meet the unique needs of persons with dementia and can enhance comfort and quality of life

Questions?

