FTD/PPA Caregiver and Professional Education and Support Conference 2012

Advanced Stage FTD and PPA/ End Stage Care March 2012

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The Palliative Care & Home Hospice Program
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Anticipatory Grief

Definition: "as the grieving process that commences when we learn of a loved one's life-threatening or terminal illness. The grief experienced before a death does not make the grief after the death last a shorter amount of time."

- Individuals realize that death is inevitable.
- Begin to imagine what their lives are going to be like without the person.
- Opportunity to complete unfinished business (saying "good-bye," "I love you," or "I forgive you").

Causes of Anticipatory Grief

Related to fears and actual or possible losses, such as:

- Loss of social life
- Loss of companionship
- Loss of usual eating, sleep, work, and recreational habits
- Loss of independence
- Loss of control, such as, being able to care for yourself or a loved one

Causes of Anticipatory Grief

Related to fears and actual or possible losses, such as:

- Fears related to life without your loved one
- Fear of losing present family structure, such as head of household, the family matriarch, or frequency of visits from family members
- Fear of starting over
- Fear of the unknown

Sensory Stimulation

Stimulation of the senses as a way to communicate, connect, stimulate and provide comfort.

Why use Sensory Stimulation?

- Verbal communication is no longer most effective way to communicate and/or stimulate
- Reduction of distressing symptoms created by sensory deprivation
- Enhancing quality of life with positive emotions and responses
- Decreasing caregiver distress, guilt and hopelessness
- Caution: may be over stimulating for some individuals

Sensory Stimulation

- Smell aromatherapy/scents used to stimulate memories (orange, lavender, lemon balm, coffee, peppermint, rosemary)
- Taste offering tastes (especially sweets) for pleasure/comfort; choking precautions
- Visual items to encourage communication and stimulate brain function (photos, ball, balloon, bubbles, flowers, baseball, lights that change color)
- Touch intervention to provide comfort (gentle hand massage, textured balls, mylar paper); caution re: fragile skin, open areas, arthritis, contractures
- Hearing familiar music to stimulate memories, relaxation and comfort (nature sounds like birds, waves, water, thunder)

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"When we are dead,
And people weep for us and grieve,
Let it be because we touched their lives
With beauty and simplicity.
Let is not be said that life was good to us,
But rather we were good to life!"

-Jacob P. Rubin