



HOSPICE AND PALLIATIVE CARE

Creative Arts Therapy Across the Continuum of Care: A Case Study Prospective



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Hospice Is...

A concept of comprehensive care for the dying when the focus of treatment becomes comfort.

Hospice Programs Offer:

- Symptom management through medication and non-pharmacological interventions.
- Psychosocial support for both the patient and family – including all phases from diagnosis through bereavement.
- Services commensurate with the needs of the patient.
- Interdisciplinary team approach to patient care.
- Specially trained personnel with expertise in end-of-life care for the dying and their families.

Creative Arts Therapy (CAT) Is...

The therapeutic use of creative arts modalities (music, art, etc.) to address physical, psychosocial, and spiritual issues related to health and wellness.



Our CAT Department – Comprised Of Two Clinical Modalities

Music Therapy

- We typically refer a Music Therapist to assess and treat specific physical, psychosocial, or spiritual issues and symptoms of our patients of all ages/caregivers that are active on the hospice program.

Art & Soul™

- Our *Art & Soul™* program utilizes art therapy to address the unique needs of children and adolescents confronting the illness of loss of a loved one; and assists families by providing the materials to create lasting keepsakes and support healthy coping skills.

Phases of CAT Parallel to the Illness Trajectory

Initial Evaluation to Hospice	→	<ul style="list-style-type: none"> • Presenting Families with the Diverse Range of Services to Decrease Anxiety When Considering Hospice • Providing Support During Evaluation
Hospice Services	→	<ul style="list-style-type: none"> • Developing Relationship • Symptom Management • Pre-Bereavement Support • Developmentally-Appropriate Education
Transition	→	<ul style="list-style-type: none"> • Symptom Management
Active Dying	→	<ul style="list-style-type: none"> • Comfort Care
Death	→	<ul style="list-style-type: none"> • Support to Family
Funeral Process	→	<ul style="list-style-type: none"> • Funeral Planning & Attendance
Bereavement	→	<ul style="list-style-type: none"> • Bereavement Support • Facilitating Transitions • Memorial Services

* Note: Phases truly mimic illness progression

Angela's Initial Evaluation for Hospice Services

- In General, patients being evaluated for hospice may come from
 - Palliative Care Program
 - Direct From Outside Source
- Angela referred from a children's hospital.
- AT provides support to Ricky Jr. (8-year-old brother) and family (both parents and grandmother) during Angela's evaluation.
- MT provides Angela with comfort measures to decrease anxiety while Admission RN assesses eligibility.
- Angela's Age: 4 years old.
- Angela's Dx: Pantothenate Kinase Associated Neurodegeneration (PKAN) – resulting in iron deposition in basal ganglia.
- Family's Hospice Goals: to keep Angela comfortable at home but are undecided about goals of care when she begins actively dying.
- Admitted to Hospice program in January.
- Note: Families often evaluate CAT during first meeting –
 - Can CAT support **OUR** needs?
 - Can CAT provide services like we had in the hospital?
 - CAT facilitates interview to determine patients and/or families goals and needs.

Reasons for Referral

- Referrals can be made for:
 - Patient
 - Caregiver
 - Other Family Members
- Physical:
 - Symptom Management
 - Promoting Comfort
- Psychosocial:
 - Treatment of Anxiety and Depression
 - Supporting Meaningful Family Communication
 - Supporting Spiritual Comfort, Ritual and Practice
- Emotional:
 - Facilitation of Reminiscence and Positive Life Review
 - Supporting Creative Emotional Expression
 - Creating legacy projects and keepsakes
- Appropriate Referrals:
 - To promote physical , psychosocial, emotional or spiritual comfort aligned with the hospice plan-of-care goals.
- When the level of need does not require CAT:
 - Simply because a patient displays an interest or affinity for music or art may not necessitate the need for therapeutic interventions.
 - CATs can also provide consultative support to families regarding the independent use of music and art to enhance QOL.
- Note: Most individuals are referred to CAT program following hospice admission.

Angela & Ricky Jr.'s Admission to CAT – Reasons for Referral

Angela

- Psychosocial needs
 - Spiritual Distress
 - Impaired Coping – anxiety and depression related to illness
 - Altered Neurological Status
 - Locus of Control
- Physical needs
 - Altered Breathing Patterns
 - Impaired Communication – dysphagia related to disease progression
 - Declined gross- and fine-motor function
 - Pain
- Emotional needs
 - Fear

Ricky Jr.

- Psychosocial needs
 - Impaired Coping – anticipatory grief and complicated mourning
 - Relationship Conflicts – feelings of isolation (parents diminished attention); desires to play with Angela but overshadowing fear
 - Death Education – “my sister could get better if Doctors gave her more medicine.”
- Emotional needs
 - Fear and Anxiety – directed towards Angela and her illness

Benefits of Creative Arts Therapy

- Offers **locus of control** to patient.
- Provides a **non-verbal form of communication**.
- Supports psychosocial and emotional needs of patients and their families in a creative way.
- Allows patient to **control their environment**.
- Provides **developmentally-based interventions** to educate children about death and dying.
- Allows patients and families to **express their feelings** about death and the dying process.
- Provides pain and symptom management.

Angela & Ricky Jr. Throughout Hospice – Building Rapport

- Creating a protected space.
- Providing comfort and support.
- Offering non-verbal “safe” mediums.
- Providing a locus of control.

Angela & Ricky Jr. Throughout Hospice – Symptom Management

- Pain Management
- Dyspnea
- Dysphagia
- Eventually transitioning to emotional support needs
- Coping Modifiers

Angela & Ricky Jr. Throughout Hospice – Pre-Bereavement Support & Education

- Decreasing anxiety while increasing opportunities to express feelings.
- Facing the prognosis.
- Disease-related education.
- Provide age-appropriate education on the death and dying process.
- Supporting Ricky Jr.'s need to partake in legacy project.
 - Mural for Angela near bed.
- Counter-acting Ricky Jr.'s feelings of helplessness and desire to provide direct comfort to Angela.
 - Creating book he could read to her.
 - Writing lullaby he could sing to her.

Angela in Transition

- Now requires enteral feedings.
- Has contractures and dystonia.
- Respiratory insufficiency leads to O2 dependence.
- Increased secretions.
- Pupils dilated.
- Disease-related dementia and hallucinations.

- CAT respects and acknowledges various grieving styles; and educates members of family.
 - Ricky Jr.'s three scenarios and wishes at the time of Angela's death and funeral.

- This phase requires much flexibility from CAT.
 - Constant reevaluations and quick adaptations to best continue to address plan of care.

- Note: Some patients are referred to CAT during the transition phase...
 - Goals focus on comfort care.
 - Art Therapy Specific Interventions.
 - Music Therapy Specific Interventions.

Angela During Active Dying Phase

- Falls into persistent vegetative state.

- CAT provides comfort measures.
 - Labored, shallow breathing.
 - Terminal restlessness.

- Of utmost importance – providing support to family who keep round-the-clock vigils at Angela's bedside.

- Legacy projects which can be completed with family and/or staff.

- Note: Some patients are referred to CAT during the active dying phase...
 - Goals and interventions are extensions of transitioning stage.

Angela's Death

- Comfort measures.
- Supporting family.
 - Offering extended family opportunities for participation.
- Age-appropriate education regarding funeral and burial process.
- Assisting with funeral planning and finalizing.
- Angela dies in March, just two months post-hospice admission.
- Note: Some patients are referred to CAT following a death...
 - Goals focus on support for family.
 - Art Therapy Specific Interventions.
 - Music Therapy Specific Interventions.

Angela's Funeral

- Assistance with funeral planning, including taking Angela's and Ricky Jr.'s wishes into consideration.
- MT provides musical offering during funeral.
- AT and MT provide support to family members, creating a safe therapeutic space for children who need additional support, throughout the funeral process.
- Overall support to members of the family.
- Legacy projects.
 - Artwork
 - Music and/or pre-composed songs
 - Shared Chanting

Ricky Jr. Receives Bereavement Support

- CAT interventions are often short-term:
 - Assessment and/or re-assessment
 - Followed by 5-6 sessions
 - Facilitating transition to children's bereavement group.
- AT and MT provide community outreach and debriefing sessions at Angela's school.
- Note: Some children (usually siblings) are referred to CAT for bereavement...
 - Goals focus on support for family.
 - Art Therapy Specific Interventions.
 - Music Therapy Specific Interventions.

Memorials & Services of Remembrance

- Importance of rituals.
- Benefits for families and survivors.
- Providing support to staff both internally and externally.

Questions?

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