



A Case in Point:

Sara was diagnosed with cancer at age two and died at age six. During this time period she experienced cycles of being ill, getting better and finally not getting better. This Child Life Specialist was fortunate to have worked with her in three settings – hospital, clinic and the George Mark Children's House (GMCH).

Sara enjoyed playing with Play-Doh. Starting six months prior to her death, many of her play themes began to revolve around death and grieving. She would use the green houses from Monopoly to make coffins, always creating elaborate grieving scenes at the cemetery. Sara carefully covered the coffins with "grass" and often created headstones. While hospitalized, the coffins usually represented a burial space for deceased relatives. At GMCH, however, the represented deceased person was alive, and she often took the same name as her mother. The headstone she created for this person marked the year of her own death.

Interesting to note, Sara hid these play themes from her parents, stating they did not like it when she "played cemetery". Sara's explanation of her play heavily focused on how the mourners felt. They always cried, were sad, and spoke of how much they would miss the deceased person. Although Sara never spoke of her own impending death, it seemed as if she was assuring herself that her loved ones would mourn the loss of her life. During our last time together, she told me that even though the body was buried in the ground, the thoughts and feelings were in heaven with a special angel. The angel was a young girl.

Based on my ongoing relationship with Sara, I believe she used these play opportunities to safely express her feelings in ways that were not frightening or overwhelming to her.

Case study provided by:
Pat Frasca, Child Life Specialist
George Mark Children's House

Caring for a Child Approaching the End of Life & Keeping the Family Together: Ways Dying Children & Their Siblings Communicate Their Needs



Children facing a life-threatening illness and their siblings often need to express their pain, anger, sadness, confusion, fear, love and hope. While some are able to communicate their experiences verbally, many rely upon symbolic, nonverbal language through art and play; allowing them to express feelings and communicate experiences which may be impossible for them to put into words. Drawings can provide a window into a child's innermost, private self. Through art and play children are more able to cope with the ordeals of their illnesses and come to terms with their experience and prognosis. The expressive arts, which include drawing, painting, claywork, play, writing, storytelling, music, movement and sandplay allow for unconscious feelings to emerge and find form in the outer world.

Expressing feelings through art therapy – Susan Bach, author of *Life Paints its Own Span*, has repeatedly found that children's drawings reveal both their psychological and physiological understanding of what is happening to them. Even before many children are consciously aware of their prognosis, their artwork may indicate a preconscious knowledge of their illness and its outcome (see *A Case in Point*). A child might begin to draw spontaneously or be guided with suggestions such as: "draw your feelings about your illness" or "draw someone real or imaginary who can assist and support you during this time." In *Armfuls of Time*, by Barbara Sourkes, an 8 year old boy drew his feelings after finding out he had leukemia: "I turned pale with shock and chose yellow - a pale color. Scared is red for blood...I was mad -black- about alot of things: staying in the hospital, bone marrows, spinal taps...I was sad -purple- that I didn't have my toys and that I was missing out on everything. I chose blue for lonely and green for hope..." ([click for art examples](#)).

Effects of different art mediums – it is important to be aware that different art media may elicit different responses. Structured art materials such as colored pencils, felt-tipped pens, and collage will encourage focus, containment and a sense of mastery and control. Unstructured materials such as paint and soft clay may serve to loosen inhibitions and allow access to the unconscious. If a child appears overwhelmed during their art process, the medium can be changed from paint to colored pencils or cutting and pasting on a smaller sized paper for an increased sense of control, grounding and containment. Engaging in a dual drawing with a child on the same sheet of paper provides safety and reassurance as the adult mirrors the child's experience by drawing similar images or providing symbolic support such as drawing a helper or environment to protect them.

Interpreting the artwork – In *Drawings from a Dying Child*, Judy Bertoia states that: "Just as we can never really know the subjective experience of another person's life or dreams, a viewer can never be certain of the meaning of another's drawings." Rather than jumping quickly to interpret their imagery, it is best to carefully listen to the child's own explanation and associations. Start with open-ended questions such as "Tell me about your drawing", "Is there a story that goes with this?", "How did you feel while you were painting this?", "What does the color blue mean to you?" This gives the child the opportunity to share their experience in a way that is meaningful to them rather than having an adult's interpretation or projection imposed on them.

Art therapy isn't just for the children – As parents and caregivers, we must also find ways to care for ourselves as we accompany the children on their journeys. Using the same art materials and methods, draw your own feelings about what this process has been like for you. Draw your love, grief, anger, helplessness, strength, hope, growth, inspiration, heartbreak and healing. Paint or sculpt the bond that you share with the children, a profound heart-felt connection that will endure and expand beyond their death.

Andrea Bass, M.F.T & Board Certified Art Therapist

"Once you have a disease, people treat you as if you're not capable. Even though it's not true, it makes you feel really bad about yourself." *Anonymous 11 yr old; Armfuls of Time by Sourkes*

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Examples of Art Therapy

All art examples adapted from:

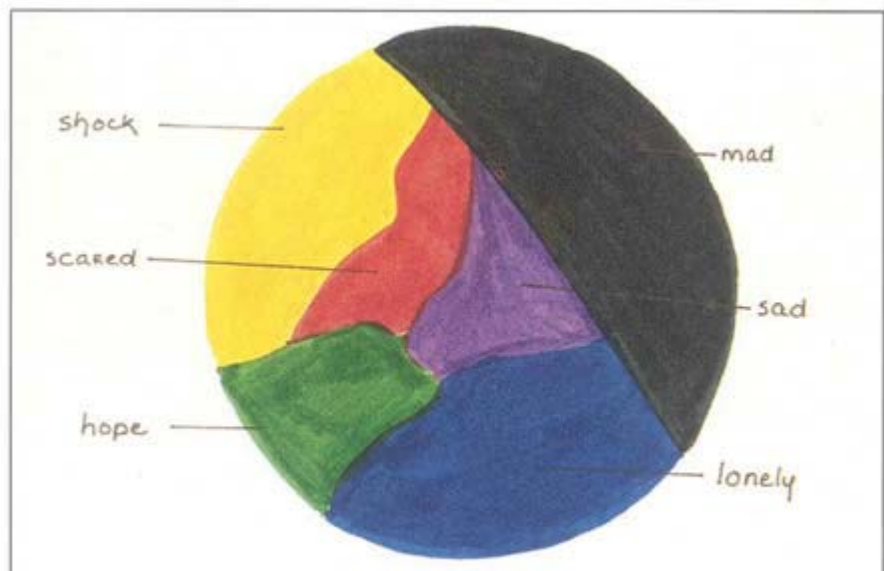
Armfuls of Time:

*The Psychological Experience of
a Child with a Life-Threatening Illness*
by Barbara M. Sourkes, Ph.D.

Caring for a Child Approaching the End of Life & Keeping the Family Together: Ways Dying Children & Their Siblings Communicate Their Needs

Example 1: Color Plate I

"When I heard that I had leukemia, I turned pale with shock. That's why I chose YELLOW -- it's a pale color. Scared is RED -- for blood. I was scared of needles, of seeing all the doctors, of what was going to happen to me. I was MAD [BLACK] about a lot of things: staying in the hospital, taking medicines, bone marrows, spinal taps, IV's, being awakened in the middle of the night. I was sad [PURPLE] that I didn't have my toys and that I was missing out on everything. I chose BLUE for lonely because I was crying about not being at home and not being able to go outside. GREEN is for hope: getting better, going home, eating food from home, and seeing my friends."



COLOR PLATE I. *How I felt when I heard that I had leukemia*

Example 2: Color Plate II

"RED is for shock -- it's like coming to a stoplight, or like being hit by a bolt of lightning. Anger is BLACK because it's a very, very dark feeling. You feel scared all the time of what is going to happen to you [PURPLE]. Alone is BLUE, for tears, because you are so sad. I chose YELLOW for hope, because it's a sunny color, with a lot of light. Helpless [GREEN] is little in my drawing, because that's just how you feel -- tiny and scared. I made confused a mixture of all the colors together. You're just confused about everything going on and how this could all be happening to you."



COLOR PLATE II. *How I felt when I heard that I had cancer*

Example 3: Color Plate XXIV

"An eight-year-old boy who has just relapsed worked on this picture in the playroom. In response to the child life specialist's query about all the "eyes" that he had so carefully glued onto the paper, he explained: 'It's God watching over me!'"

Example 4: Figure 2

"An eight-year-old boy hastily drew stick figures to illustrate the members of his family. One brother was playing baseball, another playing hockey, and the patient himself was bald, had no mouth, and was not doing anything. Neither were the parents engaged in any activity. When asked what changed in his family after he became ill, the boy immediately scrawled: "They all cry." This is a striking portrait of anticipatory grief within the family system."



COLOR PLATE XXIV. *God watching over me*



FIGURE 2. *Family: They all cry*

"Once you have a disease, people treat you as if you're not capable. Even though it's not true, it makes you feel really bad about yourself." *Anonymous 11 yr old; Armfuls of Time by Sourkes*