



# E - NEWS

A program of the  
National Hospice and Palliative Care Organization



## ChiPPS Pediatric Palliative Care Newsletter – Issue #5; September, 2006

### Teens Who are Coping with a Life-Threatening Illness

*The specific subject of the remainder of this issue of the newsletter is adolescents who are coping with a life-threatening illness. Here is a brief Table of Contents highlighting the articles included in this document.*

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*The Pregnancy Loss and Infant Death Alliance released the following position statement, dated April 7, 2006:*

**Position Statement: When bereaved parents hold their baby's body for any length of time after death, there is little or no impact on postmortem pathology studies.**

## **BACKGROUND**

Many parents benefit from repeated and extended opportunities to have close contact with their deceased baby's body, including touching, examining, holding, cuddling, and kissing. For parents who want to have close and extended contact with their baby, this nurturing experience affirms their baby's existence and importance, validates their role as parents to this child, offers meaningful opportunities to express their love and devotion, and cultivates treasured keepsakes and memories. This experience can also help parents process the traumatic events surrounding their baby's death and experience a more gradual goodbye, both of which are productive components of healthy grieving.

Parents also benefit from witnessing others gently touching and holding their baby. The tender and reverent presence of others honors their baby, and offers opportunities for supportive sharing of memories over the normally lengthy grieving process.

Finally, parents benefit from having their cultural and spiritual needs respected. In order to honor the parents' preferences around the care of their baby's body after death, health care practitioners should ask each family to explain their traditions and beliefs.

## **SUMMARY**

When parents hold their baby's body for any length of time after death, the impact on postmortem pathology studies is minimal to nonexistent. In most cases, etiologic evaluations can be delayed for hours or a day without significant consequence on their being informative. In specific cases, some examinations will be of greater value if performed within 24 hours after death, and the pathologist should be contacted early to give advice. Especially when early autopsy is indicated or required, the parents benefit from meeting the pathologist who shall perform the autopsy.

After delivery and until the mother is discharged, the baby's body can stay in the room with the parents as much as they desire. When the baby is not with the parents, refrigeration is advised in order to maintain the integrity of the skin and to reduce the normal (though minor) proliferation of any pathogens that were present at the time of death. The baby's body can be placed in a warming unit or wrapped in a warm blanket prior to being held by the parents. For many parents, the benefits of extended and repeated opportunities to spend time with their baby's body far outweigh the benefits of an expedited autopsy.



## FACTS TO KEEP IN MIND

- When parents hold their baby's body for any length of time after death, this has minimal impact on postmortem pathology studies.
- Most etiologic evaluations can be delayed for hours without significant consequence on their being informative, including radiographs, postmortem assessment, and clinical examination, or maternal examinations such as Kleihaur-Betke testing.
- Delays can affect microscopic examination of tissues, but rarely are microscopic studies of tissues from the baby crucial in identifying a cause of death, and these studies are not significantly impeded by delaying examination.
- Even though successful growth of cells from the deceased body's tissues is affected by delays in obtaining and processing samples, successful cultures can often be obtained even if sampling is delayed for 24 hours after death.
- Cellular growth for chromosome studies of samples from the baby's body will be more likely to be successful if cells are obtained within a few hours, but genetic and metabolic skin samples can be obtained by the pathologist quickly and unobtrusively, so that parents can spend as much time as they want with their baby's body before and after the procedure.
- When obtaining tissue samples for cytogenetic evaluation after an intrauterine death, the most crucial samples are *placental* ones. These should be obtained as soon as possible after delivery, and most often, the placental samples will be sufficient.
- After an intrauterine death several or more days before delivery, postponing autopsy for another day or more will not affect the results.
- As technology progresses, current cytogenetic methods that require growth of tissues are being supplanted, in whole or part, by molecular methods that don't require cellular growth (fluorescent in situ hybridization, microarray comparative genomic hybridization, etc.) and delays will not affect postmortem evaluation.

## GUIDELINES

Delaying autopsy allows parents to spend meaningful and significant blocks of time with their baby after death, and the impact on postmortem pathology studies is minimal to nonexistent. When parents are able to have extended and repeated opportunities to spend time with their baby's body, the psychosocial and emotional benefits to them can significantly outweigh the benefits of prompt postmortem evaluation.

After delivery and until the mother is discharged, the baby's body can stay in the room with the parents as much as they desire. When the baby is not with the parents, refrigeration is advised in order to maintain the integrity of the skin and to reduce the normal, though minor, proliferation of any pathogens that were present at the time of death. (Pathogen proliferation poses an insignificant risk to the parents.) The baby's body can be placed in a warming unit or wrapped in a warm blanket prior to being held by the parents.

When autopsy is indicated or required, contact the pathologist to request advice on whether there are some examinations that will be of greater value if performed within 24 hours after death. Also, parents benefit from meeting the pathologist who shall perform the autopsy. Making personal contact enables the pathologist to reassure the parents that she or he will take good care of their baby, and this contact can increase autopsy rates. Especially when samples need to be collected within 24 hours, the pathologist can give the parents realistic and reassuring



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information about what the autopsy consists of, and what the baby will look like when he or she is returned to the parents.

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Additional information about this statement and its contributors can be obtained from the Pregnancy Loss and Infant Death Alliance, P.O. Box 658, Parker, CO 80134; tel. 1-888-546-2828, press 3; fax 303-649-9320; [www.PLIDA.org](http://www.PLIDA.org).



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## The Adolescent Living with a Life-Threatening Illness: Psychological Issues

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*So much of adolescence is an ill-defined dying,  
An intolerable waiting,  
A longing for another place and time,  
Another condition.*

*Theodore Roethke  
(1908-1963)*

Roethke captures the essence of adolescence: the quest, the restlessness, and the inner turbulence that accompany the opening of new horizons toward the future. The presence of life-threatening illness, whether newly diagnosed in adolescence, or as a pre-existing condition, adds layers of complexity to what is already in flux. In the words of nineteen-year old Katharine, who had been diagnosed with osteogenic sarcoma at the age of sixteen:

*Younger children are not developed in themselves yet, in their own persons, in their own individualism. They can still be with their mother. Older people are away from their mother; they're detached, more adult. When you're in the middle, parents don't want to let you go. You want to be set free a little bit, but you want to be able to come back. I just felt that I was denied any sort of chance. I wish I could look back and see: "Would Katharine have been popular? Would Katharine have had lots of boyfriends? Would Katharine have starred on the varsity?" I look now, and would that have been what I wanted? I don't know. I never had the chance to find out. Instead it was decided for me: "You are going to mature very fast right now. You have to make life-and-death decisions. You have to accept things that children who are young adults between the ages of thirteen and nineteen don't normally have to face." It's like: "Grow up right now and become what you have to become to deal with this." I never had the chance to be sweet sixteen.... I had to automatically be an adult, and it was very hard.  
(Sourkes, 1982, p. 101)*

This article will provide a brief overview of the psychological issues that confront the adolescent living with a life-threatening illness, through the dimensions of identity, autonomy/dependence, and future orientation. One must always be mindful, however, that the spectrum of development is highly variable and fluctuating among adolescents, as are differences attributable to cultural and ethnic background.

### Identity

The quest for identity is the foremost task of adolescence (Erikson, 1968). It is the period of life when defining and sharing oneself outside the sheltered context of the family, as well as envisioning the future, becomes paramount. A life-threatening illness invariably alters the adolescent's sense of personal identity. Whereas the illness may initially be perceived as an



external intruder, over time it transforms itself into an internalized part of the adolescent's physical and emotional being. This process is often noted through subtle shifts in language; e.g., "the illness" becomes "my illness." The risk for an adolescent is when his or her identity becomes overwhelmingly that of "a patient" rather than that of "a teenager who is living with/has an illness/condition."

Restrictions imposed by illness and treatments interfere with experiences through which adolescents ordinarily develop their sense of competence, self-worth, and positive self-esteem. School is the defining structure of "normal" life for all children and adolescents, and affords opportunities for achievement in both academic and extracurricular/social domains. Yet, school attendance for adolescents with a life-threatening illness is often sacrificed to hours spent at clinic visits, outpatient treatment, hospitalizations, and home. Furthermore, physical limitations from specific symptoms and handicaps (whether temporary or permanent) can be profoundly disruptive. Overwhelming fatigue commonly limits adolescents' ability to remain in school full-time and thereby reduces opportunities for learning as well as socialization.

*When asked about the illness's impact on her life, a nineteen-year-old responded, "I wasn't like this before. I had interests. I went out with my friends. I used to take acting and dance classes. I had goals. Now I can hardly get out of bed."  
(Brown & Sourkes, 2006, p. 593)*

The effects of illness and its treatment on physical appearance can also influence adolescents' developing sense of self. Physical changes of puberty bring about heightened concern with body image for all adolescents. In our society, self-image and worth are all too bound up with outward appearance. Thus, visible markers of illness, including, for example, stunted growth, obesity, emaciation, amputation, wheelchair dependence, and hair loss, place these adolescents at great risk for poor body image and related feelings of inferiority and low self-esteem. Compounding their own difficulty in adjusting to an altered body image is their fear of others' reactions to their appearance. Peers—usually responding out of their own discomfort and fear—may shy away from or even taunt the ill teens, only serving to reinforce their belief that they no longer belong. Such shame and embarrassment can lead to adolescents refusing to return to school and withdrawing from other activities. In turn, the maintenance of preexisting relationships and the development of new peer relationships are hindered.

*Following a long course of steroids and an extended absence from school, a sixteen-year-old expressed reluctance to participate in social activities with peers from school, stating that no one would recognize her since she had become so "fat."  
(Brown & Sourkes, 2006, p. 593)*

*Katharine reflected on how she had looked and felt when her weight had dropped to seventy pounds during chemotherapy: "It's very hard. You lose all self-pride and self-respect. You lose 'self' really, because physically you lose so much weight."  
(Sourkes, 1982, p. 103)*

The body is the focus of illness, and sexuality is an integral part of that same body. Physical effects of the disease and its treatment may interrupt, delay, or prevent secondary sexual development and thus complicate adolescents' emerging sense of sexual identity. Fears of loss of sexual functioning often lurk in their minds. Although adolescents tend not to initiate the topic



(in part, sensing many professionals' discomfort!), most are relieved to voice their questions and concerns when a team member with whom they feel comfortable broaches the subject.

*An eighteen-year-old who had had a leg amputated had expressed fears about his sexual functioning, and about how his girlfriend would react. On a clinic visit shortly after his surgery, he greeted his psychologist: "You'll be glad to know I still work!" Before she had time to respond, the boy added, laughing: "I was glad, too!"*  
(Sourkes, 1992, p. 280)

### **Autonomy and Independence/Dependence**

During a time of progressive separation from parents and increasing autonomy in the outer world, adolescents who are ill are catapulted back into an enforced dependency. They require assistance with the most basic of tasks, such as personal hygiene or eating. They must endure a lack of privacy over their physical and emotional boundaries at exactly the time that self-control is so paramount developmentally.

*Katharine explained that no matter how much she needed her family to help: "This is my cancer, this is my illness, it is not yours. And don't make it yours."*  
(Sourkes, 1982, p. 99)

Adolescents' efforts to maintain or regain a sense of control may manifest as rebellion or refusal to follow the prescribed treatment regimen, leading professionals to label them dismissively as "difficult" or "noncompliant." Parents, fearing the possible repercussions of such behavior may become increasingly vigilant, punitive, or inflexible in their parenting style, in turn creating heightened conflict. Alternatively, adolescents who have come to rely primarily on others for extended periods of time may become overly dependent and less confident in their own abilities to cope with the challenges at hand.

The very nature of illness, treatment, and the medical environment makes adolescents acutely vulnerable to a sense of loss of control. Any approaches or techniques that increase adolescents' participation and choices in the situation, from the most concrete (e.g., scheduling of medications or appointments) to those of symptom relief (e.g., self-hypnosis) to the most profound and abstract (e.g., treatment decisions) will increase their sense of mastery and esteem.

The desire to fit in with peers may also be at odds with restrictions of the illness or treatment regimen. Adolescents who are seeking acceptance may behave in ways that put their health at greater risk. Examples include: a teen with cystic fibrosis who feels pressured to smoke while out with friends; or a severely immuno-compromised teen who refuses to wear a face mask in public. Adolescents in general tend to be impulsive and present-focused, with limited ability or willingness to consider the possibility of a negative outcome. This is particularly the case when no immediate consequences are evident. Adolescents' sense of omnipotence, or invulnerability to potential negative consequences, only compounds the problem. Thus, even adolescents who "know" that their health status is precarious may skip medications or other therapies with the reasoning that: "Nothing will happen to me." It is often not until late adolescence or early adulthood when an adequate appreciation of hypothetical future consequences of illness begins to emerge with more gravity and consistency.



Milestones of increasing independence for adolescents, such as obtaining a driver's license, may be delayed or missed altogether. They graphically symbolize how the illness has disrupted the normal passages away from childhood toward adulthood.

### Future Orientation and Goals

*I turn to the first page, which is not a part of the journal, but a private goal sheet not meant to ever be seen by anyone. Of course I have many more goals than are written here, but these are the two most important ones, the ones I must accomplish before dying in order for my life to have been worthwhile....*

1. lose virginity

2. make a contribution—publication of journal

*(Sixteen-year-old boy with brain tumor, in novel by Schreiber, 1983, p. 22)*

Adolescence is a time of great anticipation as teens ponder who they will become and what they will accomplish. Yet, consideration of future goals can be complicated and poignant for adolescents who are living with a life-threatening condition.

Academically, these adolescents may be performing months or years behind peers as a result of prolonged school absence or the cognitive effects of the illness or disease-related treatment. Well-intentioned teachers at times promote students "through the system" even if academic goals are not adequately met. While the ill students (and even parents) may appreciate this advancement at the time, upon graduation they are left unprepared for the real world. Conversely, attempts to treat ill teens as "normal" create unrealistic expectations and place stressful performance demands on them. In either extreme, these adolescents are left with diminished confidence in their ability to achieve future success. Furthermore, in circumstances of prognostic uncertainty or unexpected medical setbacks, adolescents may lose motivation, asking themselves, "What's the use of committing to this?" If their attitude of hopelessness and despair endures over an extended period of time, future-oriented behaviors may cease, leading to further withdrawal and depression.

The potential or actual loss of fertility becomes more salient as adolescents begin to contemplate long-term relationships and parenthood. New options in reproductive technology, both for the present and the future, are presented at the time of diagnosis and treatment. Regardless of these advances, however, adolescents often must confront another facet of loss.

*A seventeen-year-old girl who had been treated for uterine cancer cried, "The biggest scar is not having my own babies." Her grief was palpable and profound.*  
*(Sourkes, 1992, p. 281)*

The overarching task for adolescents living with a life-threatening condition is to learn to tolerate the uncertainty of their life condition as they move forward through time. Their challenge is to create a balance between the demands of their illness and their hopes for the future, while finding meaning in their present relationships and accomplishments.



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## Implications for End-of-Life Care

*I was brought up to believe that life is a gift. God gives life as a gift with no strings attached. It should be a given, just to live. Then if you want to work to be different things, you work for that. But you shouldn't have to struggle just to live.*  
(Reflections of an adolescent just prior to death)  
(Sourkes, 2000, p. 265)

*A clinical nurse specialist reflected on her conversations with Rachel, a seventeen-year-old girl living with cystic fibrosis, during her stay at Canuck Place in Vancouver, Canada (the first freestanding pediatric hospice in North America). "Rachel said very seriously that when she is to die, she wanted to be here in Canuck Place, in a hospice surrounded by friends and family, and surrounded by people that knew how to take care of her...and she was talking about the nurses and the doctors that can help her not feel scared. And then she said: 'But I have another way that I'd like to die.... I would like to be sitting on my front porch, wrapped in an afghan in a rocking chair and my husband holding my hand.'"*  
(Kuttner, 2003)

The capacity for and role of decision-making on the part of adolescents has recently come into sharp focus in the field of pediatric palliative care, from clinical, legal, and ethical perspectives (Sourkes, et al., 2005; Institute of Medicine, 2003; NHPCO website). In light of all the complex developmental issues reviewed here, it is evident that each adolescent deserves comprehensive evaluation and follow-up (medical, nursing, psychological, social, and spiritual). While such interdisciplinary teams do not exist in many settings, it is incumbent upon the available professional caregivers to approach the adolescent with respect—to “go for the adult” in the adolescent—and then adjust to whatever level that adolescent actually prefers.

*A seventeen-year-old boy with hemophilia-HIV referred to his HIV condition exclusively as an “immune system disorder,” although he was knowledgeable about all the necessary blood and safe-sex precautions. On each of his admissions, when the physicians asked him whether he had any questions, he would calmly shake his head “no” and say: “If you have anything else to discuss, you can talk to my parents.” Although the team was chagrined at times with his non-involvement in decisions, he was clearly comfortable in handing that responsibility to his parents, while avidly continuing his schoolwork and seeing friends up to the time of his death.*

In our clinical experience, we have encountered many professionals who feel that adolescents are the most painful age group to face: just as they are beginning to negotiate an independent existence, that “moving forward” is dramatically disrupted or irreversibly halted. Yet, in counterpoint, others attest to the adolescents’ resilience, maturity, and sensitivity—a life spirit that touches us both personally and professionally—and enables us to continue our work with these young people.

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## Frequently Asked Questions: Adolescents Coping With Life-Threatening Illness

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**Establishing independence is a major developmental task of adolescence. Coping with a life-threatening illness threatens this independence. How can hospice and palliative care team members assist adolescents in establishing independence?**

Team members can encourage and assist adolescents in taking part in decision making regarding their care. This may include decisions regarding treatment procedures, scheduling visits with team members, or whether or not to attend school.

**How does a life-threatening illness affect peer relationships of adolescents?**

Adolescents derive support from their peer relationships. Anything which makes them feel different may cause isolation. The diagnosis itself makes them feel different. The necessary medical appointments and hospitalizations cause absences from school which creates even more isolation.

**What can team member do to lessen the sense of isolation teens living with life-threatening illness feel?**

Encourage involvement with peers. Encourage teens to remain involved (as much as possible) in existing groups—school groups, church groups, etc. Encourage attendance in school when able and arrange to make home visits around school hours. Encourage families to maintain as much normalcy as possible. Team members can also make adolescents aware of support groups and/or web resources they may access as a link to other adolescents who are coping with life-threatening illness.

**How can team members help adolescents cope with changes in body images?**

Life-threatening illness, treatment, and medication can bring about changes in appearance—weight loss or gain, hair loss, etc. Team members can link adolescents with volunteers, friends, or other resources that can assist them with clothing, make-up, wigs, etc., to make them feel better about themselves. Again, linking with other adolescents who are experiencing some of the same issues with body image will be of tremendous support.

**How can team members best communicate with adolescents?**

Building rapport is key, since teenagers may be reluctant to trust adults. Listening is also essential. Don't focus all the communication with the parent; try to spend some one-on-one time with the adolescent. Adolescents are developing their own identities. Get to know the adolescent as an individual and find out what is most important to that particular adolescent. It is also important to be aware symbolic and non-verbal communication.



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## Can Mature Minors Refuse Life-Sustaining Medical Treatment?

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While there is no universal right to die in the United States, adults can refuse unwanted medical treatment. However, children under the age of 18 have no such right of autonomy over their medical care. Nonetheless, chronically-ill children with life-threatening illnesses are often medically savvy. They may understand the nature and course of their illness and be experienced with many medical interventions and procedures. By definition, life-sustaining medical treatment can only *sustain* life, it cannot save life or cure a child's disease. Examples include mechanical ventilators, chemotherapy, and artificial feeding. Children often have experienced these life-sustaining interventions during the course of their illness and do not wish to experience them at the end-of-life stage.

Mature minors are defined by common law as adolescents who are determined to have decision making capacity. Decision-making capacity is defined by the American Academy of Pediatrics (AAP) as (1) the ability to understand and communicate information relevant to a decision; (2) the ability to reason and deliberate concerning the decision; and (3) the ability to apply a set of values to a decision that may involve conflicting elements. The AAP Committee on Bioethics recommends that physicians caring for chronically-ill children assess their decision-making capacity and if they are determined to be mature, ascertain their wishes on life-sustaining medical interventions.

Unfortunately, the legal system does not offer an easy solution for mature minors and their health care decisions. A terminally-ill child is unlikely to file a lawsuit against their parents or health providers for unwanted medical care and there is no guarantee it would be successful, unless they are an emancipated minor. An emancipated minor is 14 years or older and has been determined by a court of law to be able to live apart from their parents and who handles their own financial affairs. Thus, health care providers have a responsibility to solicit minor's wishes and advocate for them.

All too frequently, healthcare providers and parents are reluctant to discuss palliative care options with children. There is often a belief that children can't handle it. Yet children do think about the future and frequently do better when they are given concrete choices regarding their care.

### **We need more time**

A common barrier, in today's busy health care environment, to discussing palliative care options is lack of time. Health care providers must find time to build trust and rapport with a child and their family. In order to have full, meaningful, discussions, with clear outcomes, enough time must be aside to answer the child's questions and for ensuing follow up questions. Determining and recording the child's wishes may be difficult and may require a series of time-consuming conversations.



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## Fear of the outcome

Asking a mature minor what kind of interventions they do and don't want necessitates dealing with the outcome. Health care providers are often afraid to solicit a child's wishes because they may not be able to honor them. If we solicit a clear preference, we are ethically obligated to discuss the child's wishes with other members of the health care team and the child's parents even if it causes conflict between the interdisciplinary team, the parents, and the child.

Health care providers are often reluctant to discuss the child's wishes with the parents because it may burden them with further anguish. When children are terminally ill we sometimes start to place high value on what's best for the parents and the decisions they will have to live with after the child is gone. We want the parents to feel they did *everything possible*.

## What can we do?

We must put the focus back on the patient and their wishes for their life. We must invest the time to determine if a minor is mature, solicit their wishes, and try to honor them. While a child cannot legally have an advance directive, the AAP recommends soliciting a child's assent for treatment. Institutions can develop policy to solicit every mature minor's wishes and record it on a standard form as a matter of rote. While the form would not have the legal standing of an advance directive, all those involved in the minor's care would have a clear understanding of what the patient wants. The recorded wishes should have a significant impact on the treatment plan. Honoring a child's dying wishes not only allows more control over their own death; health care providers and parents can feel satisfied that they did not force unwanted or invasive treatment on a dying child.



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## Issues of Sexuality amongst Adolescents with Life-Limiting Conditions

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Sexual development is a key developmental task of adolescence. Sexual development is an ongoing process that begins in infancy, and involves being and feeling accepted by peers, exchanging affection, and sharing thoughts, feelings, fears, etc., with another. However, the sexual development and functioning of adolescent palliative care patients has received little attention.

### Challenges to Sexual Development

Adolescents who are receiving palliative care face multiple challenges to their sexual development and functioning. The nature and impact of these challenges will vary based on the adolescent's phase of development, age, condition (acquired v. congenital), and level of social and sexual development.\* A brief overview of these issues is presented below.

Many conditions cause adolescents to miss large amounts of school and associated social activities. Missed opportunities and social isolation limit the adolescent's normative social interactions, including opportunities to receive support about their sexuality from and participate in sexual experimentation with peers (Easson, 1995).

The adolescent task of cultivating self sufficiency and independence is severely challenged by progressive conditions. Increasing dependence may hinder the teen's sense of self, relationship with his/her body, and confidence, as well as limiting sexual outlets—key ingredients of sexual development.

Physical development is another key ingredient in sexual development. Normal physical development is dramatically altered both by the disease process and treatment (e.g., immunosuppressant therapies), and may impede sexual functioning and comfort (Freyer, 2004).

Several studies have documented discrepancies in the amount of information about sex given to healthy adolescents versus adolescents with life-limiting conditions and disabilities (e.g., Berman, Harris, Enright, Gilpin, Cathers, & Bukovy, 1999; Cromer, Enrile, McCoy, Gerhardstein, Fitzpatrick & Judis, 1990). Education with these adolescents tends to focus on limitations and vulnerabilities related to sexuality rather than the need for intimacy, touch, and viable options for sexual expression (Berman et al., 1999).

Finally, enduring a life-limiting condition during adolescence impacts the meaning and values that patients place on their lives, health, and relationships (e.g., Gray et al., 1992; Parry, 2003). The changes in one's values, perceptions, and expectations that occur throughout their illness course have been referred to as response shift (Sprangers, 2002). Adolescents with life-limiting



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conditions and/or who are nearing the end of their physical lives likely experience response shifts relating to their expectations about life, including sexuality and sexual functioning.

Professionals may assume that an adolescent who is preparing to die and/or is seriously disabled does not need information about his or her sexual functioning and possibilities. Although it is true that the lived experience, goals, and values of adolescents living with such conditions *may be* different than those of healthy adolescents, attention to their sexuality and sexual knowledge is important for all adolescents.

### **Ways to Promote the Sexual Development of Adolescent Palliative Care Patients**

Sexuality is often not included in assessments of well being of adolescents with life-limiting conditions and is considered to be under acknowledged (Eiser & Morse, 2001). Acknowledging this fact is one of several things that health care professionals can do to cultivate the sexual development of these adolescents. Below are listed additional ways in which health care professionals can support the sexual development of adolescents with life-limiting conditions.

#### **Discuss the sexual needs, desires, and questions with adolescent patients and families.**

Health care providers are encouraged to inquire about sexuality in a delicate, comfortable manner, using specific, direct questions in language that is developmentally appropriate. Appropriate questions will vary based on the adolescent's level of cognitive, social, and emotional development, family values and culture, as well as the adolescent's level of sexual experience and prognosis.

#### **Provide adolescents with information about sexual functioning**

Health professionals are encouraged to consult recommendations for discussion about adolescent sexuality (e.g., SIECUS, 1996), and include information about physiology, sexual functioning as it relates to the adolescent's condition, feelings related to sexuality, contraception, and protection (adolescents with disabilities are at an increased risk for sexual abuse) (Berman et al., 1999; Murphy & Young, 2005).

#### **Talk about both possibilities and losses.**

While it is not unreasonable to assume that discussions about sexuality will embody some deep feelings of loss and disappointment, such assumptions lead us away from discussions of what *is* possible for these adolescents (Cheung & Udry, 2002). Such discussions can include discussion of viable ways for the adolescent to give and receive affection, to create opportunities for the adolescent to have intimate experiences, and, if in a relationship, to facilitate private time for the adolescent and partner. Such interventions can promote emotional, social, and sexual development even as death approaches.

#### **Grief work**

The standard of care within palliative care is to hope for best while providing space to process and grieve those situations in which the best cannot be. This recommendation is also useful in



working with the sexuality of adolescent palliative care patients. Discussing the adolescents' sexual desires, opportunities, hopes, and dreams, as well as the limitations imposed by reality of one's health, gives the adolescent one 'normal' experience of sexual development amidst their non-normative health situation.

\*Comprehensive discussion of sexual issues and challenges of adolescents with life-limiting conditions is beyond the scope of this article; readers are referred to Berman et al., 1999; Easson, 1995; Freyer, 2004; and Greydanus et al. 2002.

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## Adolescent Spirituality at the End of Life

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We all have our own theological and spiritual constructs; or at the very least, we embrace some particular perspective. In this presentation of two brief case studies—from two ends of the spectrum—there are recognizable similarities that may stretch our own definition of adolescent spirituality.

First, a 16-year-old female from an active Protestant household. She attends church and youth activities weekly. Being wheelchair bound, she finds play that involves her hands and mind is vitally important. At the end of life she gives written instructions regarding her funeral and her stance on the afterlife (closely modeled on denominational stances). Her death was peaceful, and those friends and family who knew her were comforted by her strongly held beliefs. She was not afraid to tell you she was “going to heaven.”

Our second case is that of a 17-year-old wheelchair bound male who was raised in a home with no spiritual training. The family has no faith community support, nor apparent spiritual foundations. The patient enjoys play, laughing, talking about cars and girls. One of his greatest joys is long convertible rides with the hospice chaplain, laughing, cranking up the music . . . enjoying life. In the last two days of his life the patient tells his mother of a deceased relative who has come in a dream to tell him that he is going to heaven and that he will be all right. The patient's primary concern was that he wanted his mother to feel as peaceful about his future as he did.

Two teens from two very different worlds in regards to spirituality came to the same conclusions at the end of life—both possessed a great peace, and wanted their families to know they how they felt, and to join them in this peaceful acceptance. In the diversity of their everyday life activities—playing, laughing, sharing love with those around them—these children clearly exhibit ways the transcendent is real to them. And I have seen this commonality without regard to the child's spiritual foundation. In many years of serving patients at the end-of-life, it has been my observation that adolescents may have the best grasp on the presence of the transcendent as they approach their final days. So, I laugh, I play, I listen, I offer a convertible ride . . . all to see the face of God.



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## Usage of Methadone in Pediatric Pain Management

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*(Dr. Saroyan is available for questions about pediatric pain and symptom management of a general nature via email.)*

### **Methadone**

Methadone is an integral part of my pediatric pain management practice. I frequently use it in cancer pain, vaso-occlusive crisis secondary to sickle cell disease, weaning of opioid dependent infants, and severe post-operative pain. This article will focus on indications primarily in the patient with cancer and is meant to be an overview for clinicians who manage pain, but don't have experience using methadone. It is important to utilize the expertise of a pediatric pain management specialist when dosing methadone.

### **Are there alternatives to methadone?**

Yes. By all means if a patient is requiring frequent doses of short acting opioid (enterally or intravenously) and (1) you are comfortable prescribing extended release morphine (MS Contin) or extended release oxycodone (Oxycontin) or the Fentanyl Patch and (2) your patients get good relief, stick to what you know.

For patients who:

- (1) weigh less than 20 or 30 kg
- (2) need long acting relief
- (3) are in a setting where a continuous infusion of intravenous opioid is not possible, consider getting a pediatric pain management specialist involved to prescribe methadone and follow the patient with you. Fentanyl 12.5 micrograms/hour as a patch (the lowest delivery amount available) is frequently too much opioid initially for an infant or toddler.

### **Is there anything else that would make me prescribe methadone?**

Methadone has two isomers that are mirror images of each other. The L-isomer has affinity for the mu-opioid receptor, and the D-isomer is an antagonist at the NMDA (N-methyl-D-aspartate) receptor. Methadone is the only opioid to work also as an antagonist at the N-methyl-D-aspartate receptor.

Antagonism at the NMDA receptor may play a role in treating neuropathic pain (2.05 Newsletter) and decrease the rate at which tolerance develops to opioids. The thought is if you are treating pain by targeting the mu receptors why not also decrease the rate at which tolerance to opioids develops and decrease neuropathic pain at the same time by antagonizing the NMDA receptor.



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### **Does methadone have side effects that are unique or different from other opioids?**

All opioids, including methadone, can cause nausea, vomiting, constipation, and sedation. Respiratory side effects can become more severe when methadone is repeatedly given because (1) methadone is metabolized very slowly and (2) its average half-life in children is 19 hours. (Morphine's half life in an adult is 3 hours.) (3) The effect at the NMDA receptor may also increase the risk of late onset sedation.

### **How do you convert from other opioids to an equianalgesic dose of methadone?**

Convert to the equivalent dose of IV morphine using an equianalgesic table. In pediatrics, IV morphine to IV methadone 1:0.1 (assuming 90% incomplete cross-tolerance). In the patient who has developed tolerance to methadone and is still in severe pain the ratio may be 1:0.25 (assuming 75% incomplete cross-tolerance).

### **Does the dose have to be changed in renal or liver failure?**

This question has to be approached on a case by case basis. In liver and kidney failure, methadone's metabolites are excreted in the stool. In patients with end stage organ disease (e.g., liver or kidney failure), conservative dosing and interval selection should be made initially and when increasing the dose.

### **What is the conversion from IV to PO methadone? Is IV methadone dangerous?**

Methadone is well absorbed by the GI tract and has an oral bioavailability of 80-90%. For these reasons, IV to PO conversion is 1:1. Methadone in its intravenous form is preserved with chlorbutanol. Chlorbutanol can prolong the QTc interval and increase the risk of fatal cardiac arrhythmias such as Torsades de Pointes. There are no guidelines in children for what dose/kg of IV methadone necessitates EKG monitoring.

### **What drug interactions are possible?**

Many! Consult with a pharmacist on your team or pediatric pain management specialist to assess risk for drug-drug interactions. Methadone is metabolized by multiple cytochrome P450 isoenzymes. Pay special attention to central nervous system depressants (e.g., alcohol, phenothiazines), anti-virals, anti-fungals, anti-epileptics, anti-depressants, drugs that prolong the QTc interval or that cause Torsade de Pointes.

### **What about the reports heard on the news of teenagers dying of methadone overdose?**

These are teenagers who were taking methadone as a "recreational" drug. They were looking for an induction of a psychotropic effect and had either taken methadone from their parent's medication supply or bought it illegally on the street. The formulation of methadone that proved fatal presented by CBS news was 40 mg tablets that were bought on the street and ingested by opioid naïve teenagers. Forty mg tablets may be used in adults with severe chronic pain whose dose has been titrated upward over time or dispensed by a methadone clinic to treat substance abuse. This high of a dose in tablet form is much more dangerous when taken by an opioid



naïve person (and/or in addition to other CNS depressants like alcohol). I recommend that you dispense methadone liquid 1mg/ml or 5 mg tablets. As always with opioids and benzodiazepines, counsel parents to lock medication safely away.

***For example:***

A fourteen month old baby has hepatoblastoma. He weighs 10 kg. He becomes very withdrawn and quiet when he is in pain. He cries if his abdomen is touched or if he is moved. His oncologist has instructed the parents to give oxycodone liquid 1 mg every four hours. The parents have been doing this for three days. The parents say that the medicine works well for three hours but that he shows signs of discomfort in the 30 minutes before his q4h dose. The dose is not sedating.

There are several ways to approach this challenging situation. Methadone starting doses published in Harriet Lane and other references are too high. The published dose is 0.7mg/kg/24 hours divided q4-6 hours PRN pain. The dosing I have practiced is more conservative and ranges from 0.15-0.3 mg/kg/day divided q 8hr. Since this patient is in severe pain and has already been exposed to regularly given opioids, I would probably start him on 1 mg po methadone q8 hours (0.3mg/kg/day divided q8h). If I was concerned about sedation or he was not having so much pain, I could start with 0.5 mg PO q8h and plan to increase the dose if frequent oxycodone rescues were needed in the next 48 hours.

An alternate way of calculating his dose would be to add up his total oxycodone usage. He is receiving 6 mg per day. 1 mg po oxycodone = 1 mg IV morphine = 1 mg IV methadone = 1 mg po methadone. Decreasing for incomplete cross-tolerance by 75-90% leads you to very different doses! Any where from 1.2 mg methadone per day (0.4 mg po q 8h) to 3 mg per day (1 mg po q 8h). The selection of how much to decrease for incomplete cross tolerance and how much to increase methadone is a difficult one. How tolerant the patient is to methadone, how much pain there is, whether or not they are sedated and still having pain, and what the goal of care is all are important factors to consider. Consult with a pediatric pain management specialist for assistance.

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The textbook *Pain in Infants, Children, and Adolescents*, 2<sup>nd</sup> edition edited by Schechter, Berde and Yaster, and published in 2003 by Lippincott Williams and Wilkins is a "must have" for any clinician treating pain in the pediatric population. Chapter 12 was a valuable source of information and references for this column.

Manfredi PL Houde RW Prescribing Methadone, a Unique Analgesic The Journal of Supportive Oncology 2003;1:216-220.



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## Immigrant Hispanic Adolescents and Their Families: Implications for Practice

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*All adolescents bridge two worlds – the world of childhood and the world of adulthood. Hispanic adolescents, however, bridge four worlds: childhood, adulthood, the world of their origin, and that of the new host society. (Quinones-Mayo, & Dempsey, 2005)*

Hispanics are the largest and fastest growing minority group in the United States and Hispanic adolescents are the largest and fastest growing minority in this age group. The term “Hispanic” first began to be used in the United States around the 1980s, when demographers started to utilize it to describe the members of a heterogeneous and fast-growing segment of the population. It has been used in a loose manner to describe people who descend culturally from the inhabitants of Spain, regardless of their race. The vast majority of immigrants in the last decade came from Mexico, Cuba, the Dominican Republic, and El Salvador. The main reason for immigration is to escape from poverty.

**I am going to take you on a journey: the journey of the Orozco family, a Mexican family who migrated to the United States, three years ago. This family consists of a mother, a father, a 16-year-old daughter, Tatiana, a 13-year-old daughter, Mariana, and a 9-year-old son, Jorge. The family crossed the Mexican border illegally; a journey filled with danger and trauma. Shortly after arriving, both parents found jobs and started to take steps to improve the financial situation of the family. They enrolled the children in school who then had to learn the English language as well as adapt to a different land and culture. Two months ago, Mariana was diagnosed with cancer. The diagnosis came as a shock because there had been no warning signs. Mariana has spent most of her time since the diagnosis going to doctor appointments to receive treatment and her prognosis is not encouraging. The use of an interpreter at the hospital where Mariana is being treated has been sporadic, depending on availability. There have been times when Mariana has had to translate for her parents about her own condition and treatment. She has had to enroll in the home bound program and her mother has had to stop working in order to care for Mariana and to be available to take her to her medical appointments. This family's journey filled with hopes and dreams for a better future has suddenly come to a halt. This family which was living comfortably is now struggling to make ends meet due to the reduced income and is trying to take in the meaning of the diagnosis of Mariana and to adjust to the changes resulting from it. How can we as practitioners help? What would be helpful, culturally, for us to keep in mind as we set out to provide assistance?**

Immigration is possibly one of the most stressful events a family can go through. It separates the family members from important relationships—relationships with neighbors, friends, and extended family members. It has a destabilizing effect on the family. In addition, children and adolescents are rarely consulted or allowed to take part in the decision to migrate and may not have had time to say good-bye to their friends and other significant people in their lives. This creates a deep sense of loss.



**Just when the Orozco family was beginning to find some stability, Mariana was diagnosed with a serious illness. This, in turn, brought destabilization again into the family system. Aside from the stress of migration, which affected all members of the Orozco family, Mariana and her sister are dealing with the stresses inherent in the difficult stage of development that adolescence signifies. On top of this, as if there were not enough stress, Mariana and her family have to deal with a life-threatening diagnosis, the anticipatory grief, fears, and a multitude of changes associated with her illness.**

Recognition of the cumulative losses and stresses is important on the part of the practitioner because they may lead to symptoms of depression, which may or may not need medication to help. When suggesting medication it is important to stress short term use of it because anything remotely suggestive of mental illness implies stigma and loss of respect in the Hispanic culture. This explains the fact that there is a low utilization of mental health services by this population.

Practitioners would benefit from grasping the contextual view of Hispanic immigrant children and their families rather than just looking at the normative developmental phases. The adolescent cannot be treated separate from the family. To assist, we must make it a joint venture of child/children, parent(s), and practitioner(s). The socioeconomic and educational level of the Hispanic adolescent and his or her family, as well as their level of acculturation into the U. S., need to be assessed because they can give the practitioner valuable information regarding variations in belief systems and value orientations. If these variables are not taken into account, the practitioner may fall into erroneous cultural stereotyping and/or oversimplification. It is recommended that we ask the adolescent and/or the family about their country of origin and that an effort is made to become familiar with the national and cultural characteristics of the country in question. This demonstrates respect for the patient's individuality which makes rapport easier to establish.

**Several changes took place in the Orozco family since immigrating to the U.S. The traditional extended family network system in which parents, grandparents, and grandchildren live close by and the husband is at the top of the hierarchy while the wife has a surrogate role had to change once in the U.S. The Orozco parents began to share the burden of providing for the family. They were doing well at this when, due to the diagnosis of Mariana, Mrs. Orozco had to stop working and return to a more traditional lifestyle but with the additional financial stress stemming from a reduce income.**

**Another factor to be taken into account as we walk on this journey with the Orozco family is the necessity to navigate through the medical system. The financial resources are quite limited and sometimes, non-existent, for illegal immigrants such as Mariana. Fortunately, with the help of a social worker at the hospital where Mariana is being treated, Medicaid was obtained for her, which decreased the stress on the family.**

It is also important to consider that, traditionally, Hispanics regard their doctors as authority figures. They develop a linear, hierarchical relationship where the doctor gives his recommendations and the patient is expected to follow them and to be rewarded by praise from the doctor. Once trust in the doctor has been established, Hispanics will rarely question the



doctor's professional opinion. The Hispanic family is more concerned with finding "a doctor who cares."

**This cultural view had an impact on the Orozco family in that it made it difficult for the parents to question the doctors because to trust in what they said was a sign of respect and the language barrier, requiring the use of an interpreter when available only made communication more difficult.**

In addition, with Hispanic adolescents, giving assent is considered a sign of respect toward anyone older than oneself, even when the individual is in disagreement with the issue in question. This is because the Hispanic family is based in a triad of values: respect, affection, and dignity.

**Hispanic youth are taught to respect others at all times, always maintaining the intergenerational line and addressing anyone older than themselves with "usted" (the formal "you"). This may impact Mariana's answers to the medical staff when at the hospital and it indicates that additional effort may need to be made to reassure her that the medical staff wants to know her wishes no matter what. The traditional family where the parents are expected to guide the children through the complexities of life is reversed when migration occurs. If the immigrant parents do not speak the new language (as is the case with Mariana's parents), then they are brought down to the level of a toddler and this may lead to loss of self-esteem and depression. The loss of dignity has a profound effect on the parents; it needs to be considered when being tempted to utilize a Hispanic adolescent who speaks English to translate for his or her parents. This also illustrates how Hispanic immigrant adolescents are bridging four worlds: childhood, adulthood, the world of their origin, and that of the new host society, in contrast to all other adolescents who bridge two worlds: childhood and adulthood.**

What is the best way to help families like the Orozcos? A good start would be to take into consideration the factors mentioned above, i.e., proper assessment of the socioeconomic, educational level of the adolescent and the family, obtaining information on the degree of acculturation and reasons for migration, educating ourselves on the customs and rituals of their country, keeping in mind the importance of values such as respect, affection, and dignity, recognizing the cumulative effect of losses felt by the adolescent and family (stemming from the migration process) prior to a medical diagnosis and how these losses are compounded by the further losses and changes brought by the illness, keeping in mind how Hispanic families view the relationship with the doctor and how important it is to be perceived as caring in order to gain trust, and giving additional reassurance that may be needed in order to elicit any questions or concerns the family or adolescent may have. In addition, in a focus group study involving immigrant Hispanic mothers raising "American" adolescents, the group members expressed that what they needed most was to be understood and treated humanely, based on their cultural definition of humanity. Isn't that what all human beings want and need?

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## Interdisciplinary Case Study

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*This case study was submitted by the pediatric hospice and palliative care team of Daniel's Care, a pediatric hospice and palliative care program of Hospice of the Bluegrass in Lexington, KY. This case study was written from the perspective of each of the core disciplines of the hospice and palliative care team, highlighting the collaborative process inherent in pediatric palliative care.*

*We invite you to submit a case study that highlights the work of your hospice and palliative care team. Case studies should provide a summary of the ill child's history and pertinent psychosocial and spiritual information. Additionally each of the team disciplines should include its own perspective of care. Submit your case studies to Stacy Orloff at [stacyorloff@thehospice.org](mailto:stacyorloff@thehospice.org).*

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Natalia is a Hispanic fourteen-year-old girl diagnosed with aplastic anemia, a rare blood disorder, living in a small community adjacent to Lexington, Kentucky. She was diagnosed at fourteen years old at Kentucky Children's Hospital in Lexington and began receiving immunosuppressive therapy shortly thereafter. Natalia also receives weekly blood transfusions. She lives with her parents and 3 siblings, including 1 older sister and 2 younger brothers. The family's main support system is extended family members.

Since her diagnosis, Natalia's family has been driving one hour each way, several times a week, for her to get check ups and treatment. The social worker at the hospital contacted the hospice and palliative care pediatric coordinator to refer Natalia and her family for services because of the perceived needs of the family (for additional support and assistance) and her poor prognosis. Natalia is receiving palliative chemotherapy at present. Her only chance for cure is to receive a bone marrow transplant coordinated by Cincinnati Children's Hospital. The Kentucky Children's Hospital Hematology/Oncology team assessed the chances of Natalia's long term survival as highly unlikely since her siblings' bone marrows do not match hers, necessitating for Natalia to receive a transplant from an unrelated donor. Due to numerous infections and absence of a matched donor, the bone marrow transplant is on hold at this time.

Natalia, her older sister and younger brother speak English fluently. Her parents and youngest brother do not speak English and have little understanding of the language. This makes communication between medical staff and family more difficult. There is a translator at the clinic/hospital. However, the translator is not always available and sometimes Natalia has to act as translator to her parents. The clinic staff is aware this is an issue. Often Natalia misses appointments. Her parents at times seem very confused about Natalia's condition and care needs. Natalia herself is very shy and often doesn't communicate her feelings to those other than her family.

Natalia's parents are hard-working and were able to live well financially before her diagnosis. Since diagnosis, Natalia's mother has quit her job in order to take care of her and accompany her to frequent medical appointments. The family's stress level due to financial struggles has increased manifold and this, in turn, affects the marital relationship. Natalia's parents had



previous marital problems which have been exacerbated due to the additional stress of their daughter's illness. The clinic social worker has helped the patient obtain emergent Medicaid as a payer source. Natalia's family had no previous insurance as they are in the country illegally. The emergent Medicaid is valid for a year.

Natalia is very close to her maternal grandmother who lives in Mexico. She expresses a desire to see her one more time. Natalia is not presently attending high school but expresses her desire to return to school as soon possible. She does not have contact with school friends at present.

Natalia has a double lumen Hickman catheter for venous access. The hospice and palliative care pediatric team nurse irrigates the catheter as well as accesses it for blood draws. The pediatric nurse is also responsible for sterile dressing changes. The goal of home support is to reduce the family's time at clinic. Due to illness and side effects of treatment, Natalia complains of headaches, itching, shortness of breath, nausea, and decreased appetite. Natalia's medications include Albuterol for shortness of breath, Benadryl, GCSF, and Tylenol for pain.

Natalia and her family are Christians and report a strong faith. However they are not affiliated with any particular church in the area.

The pediatric hospice and palliative care team (including a nurse, social worker and translator) has met with the family to discuss hospice and palliative care and illness/prognosis. Natalia's mother verbalizes numerous questions about her illness and care. She also verbalizes confusion and fear about Natalia's prognosis. Mother reports she has not fully understood medical information given to her by clinic and has been too embarrassed/intimidated to ask further questions. Natalia was quiet during most of this initial meeting but did share a little about her symptoms and feelings including difficulty sleeping and fear of changes in her body and environment. Her mother reports they are ready for palliative care and Natalia and her family were subsequently admitted to the program.

Natalia has been receiving hospice and palliative care services in her home for several months. Each discipline has approached the case utilizing their discipline-specific expertise. The disciplines currently utilized are nursing, social work, chaplaincy, bereavement, and volunteers. Other disciplines may be accessed as needed. They include allied therapists, dietary, expressive therapy, and certified nursing assistants. Natalia's Hematologist/Oncologist remains the primary physician. The hospice and palliative care team collaborates with the primary physician to provide care at home. The hospice and palliative care medical director and volunteer medical associate act as team consultants. Natalia and her family are also members of the interdisciplinary team. The plan of care for the patient and family is a coordinated effort between the patient and family and the interdisciplinary team. The Pediatric Coordinator is also providing team oversight.

## **Nursing**

The nursing plan of care for Natalia has been approached from the aspect of care planning within the interdisciplinary team. The primary area of concern is communication, not only between the patient/family and hospice and palliative care team, but also with other multiple



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medical teams. As the case manager, the responsibility of the primary nurse is to assure that all teams are communicating with each other. Open conversations regarding patient care, symptoms, emotions, and even complaints have been a priority. From a hospice and palliative care standpoint, we have facilitated communication through use of a volunteer translator who co-visits with team members. This has helped assure that the parents have the opportunity to ask questions and receive satisfying answers, instead of feeling embarrassed. When a translator is unavailable for a co-visit the language line is used.

Previously, there have been unfortunate times when Natalia has been used as a translator. This sick child not only has to hear the cold truth of her disease, but tell it to her parents. This occurred in the clinic setting due to unavailability of a Spanish translator. The hospice and palliative care team worked with the clinic team to develop a plan to prevent this. If a translator is unavailable, medical information will be communicated to the primary nurse who will then contact the volunteer translator who will relay the information to parents via telephone. This change, alone, was very helpful to the entire family.

Assessment for physical and psychosocial pain is performed on every visit. Medications are coordinated through Natalia's primary physician at the Hematology/Oncology Clinic. Emotional support to the parents of a dying child sounds like empty words, but knowing that there is someone who truly cares and supports your family is empowering.

Symptom management has been tricky at times. Natalia is shy and not always forthcoming with her feelings. In the comfort of her home, she shares her truest inner self. In the clinic, she goes into protect mode and indicates that everything is fine. Treating her symptoms of depression and anxiety, which presented with horrid nightmares, took time and patience. After involving psychiatry (at the Kentucky Children's Hospital) and educating the patient/family on medications, symptoms were controlled. Physical pain has not been a real problem. Managing her disease process with frequent blood draws and trips to the clinic for platelet infusions has been a challenge for both the patient/family and team due to frequency of blood draws and travel to and from the clinic. The hospice and palliative care nurses communicate with the clinic several times a week to manage care and decrease travel if possible. For example, blood draws are done in the home setting if possible. Once the clinic has results, the family and the hospice and palliative care team are notified of next steps: transfusion or another blood draw later in the week. Natalia has been hospitalized for a Hickman catheter infection. The hospice and palliative care team assisted in coordination of discharge and managed IV therapy at home.

Natalia has trouble understanding the need for treatment when she does not feel bad. Several discussions have ensued regarding activities that increase the risk of potential injury or bleeding (outdoor physical activities). Safe choices are not always fun choices. Creatively, there can be fun safe choices. The team has worked together to focus on what patient can do instead of what she can not (swinging, sidewalk chalk, arts and crafts activities completed outside). Finding a balance of safety and quality has been a challenge. The team also coordinated efforts to celebrate Natalia's 15<sup>th</sup> birthday since she was unable to have the traditional Hispanic celebration.

Education plays another large role in the home setting. Natalia's mother has been taught how to perform sterile dressing changes on her Hickman catheter. She also flushes the catheter



with 5ml normal saline and 300 units of heparin twice a day. She gives her daughter subcutaneous injections via infusion ports daily. She has been taught the purpose of Natalia's medications and potential side effects. Natalia receives ongoing teaching regarding the importance of taking her medication daily as prescribed by her physicians. Every visit involves a piece of education.

On-call nursing staff are utilized to handle week-end blood draws and crisis situations (high temperatures and bleeding gums). When on-call staff have been called to a pediatric home and have felt uncomfortable in a situation the primary pediatric nurse has been contacted via telephone to provide additional education and support. A translator is not available to co-visit with on-call staff so the language line is used.

Our goal at hospice is for the parents to care for and support Natalia at home while enhancing her quality of life with our support.

## **Social Work**

Natalia and her family presented with multiple issues. The social worker, together with the nurse, began work with this patient and family by educating them regarding Natalia's illness and prognosis. The social worker recognized early on how alone Natalia felt and how afraid she appeared to be about her life and about all the changes that had happened to her and to her family. Working to establish rapport and to gain Natalia's and her family's trust were the initial goals. In order to do this, the social worker took time to listen, validate, and support her and her family, offering unconditional regard at all times.

As mentioned previously both Natalia and her mother had numerous questions about her illness/disease process. They were too intimidated to voice these questions in the hospital/clinic setting; the home setting lent itself more easily to voicing their concerns. Together the nurse and social worker listened non-judgmentally to their concerns, no matter how small. Their concerns included: "Could Natalia eat pork? Was the illness temporary? Could she attend school? When can she go to the dentist?" Natalia also had fears regarding whether any changes in appearance were temporary or permanent and had questions about why certain physical activities were off limits to her (dancing, bike riding, etc.). The team discussed these concerns, and then relayed them to the staff at the clinic/hospital. Together the clinic team and hospice and palliative care home team discussed concerns and collectively were able to come up with answers that both teams agreed upon. The hospice and palliative care team then relayed the answers to the family. The hospice and palliative care social worker also worked to facilitate communication between Natalia and her family, the Kentucky Children's Hospital/Clinic staff, and hospice and palliative care team members.

Although initially Natalia wanted to return to school; it became clear in time that she would have to join the Home Bound program because of the unpredictability of her doctor's appointments and the frequency they were needed. The social worker facilitated a smooth transition into the program by explaining how it would work and by communicating with Natalia's teacher and school as necessary. Natalia's world has been dramatically reduced by loss of her natural peer group at school. She has been grieving this loss. The team social worker assisted her in understanding how normal her feelings were and by encouraging her to call her friends and to



plan activities with them as much as her physical condition allows. In addition, the social worker, understanding the importance of socialization, encouraged Natalia to discuss age-appropriate interests with her and other team members during visits.

Natalia has expressed fears of dying and has difficulty verbalizing them. This is partly from her Hispanic background. When the team social worker asked Natalia if she thought that by talking about her fears, she would make them come true, she answered in the affirmative. In the Hispanic culture, there is a great deal of superstition and this belief system has affected Natalia significantly. The social worker normalized her fears as having a real basis while, at the same time, encouraging her to find her own way to express her fears (i.e. writing them down on a piece of paper and then, burning it; or keeping a journal). Emphasis has been placed on reassuring Natalia of the fact that even though her life seems to be spinning out of control; the hospice team members are committed to respecting her wishes and to making suggestions as to different options to help her and her family. Guided imagery and other relaxation techniques have been used to address her anxiety. Since Natalia expressed the wish to see her grandmother again the social worker contacted the Make-a- Wish Foundation and they agreed to make patient's wish a reality.

Another cultural element present with Natalia is the fact that her diagnosis occurred just before her 15<sup>th</sup> birthday (Quinceañera), which is the equivalent of the sweet 16<sup>th</sup> birthday in the United States. (Natalia was 14 years old when diagnosed but turned 15 several months later). The team worked together to help Natalia accept that she would not be able to have the customary celebration (including dancing) because of her physical activity restrictions. The team made efforts to celebrate her birthday with her and made her feel extra special on that day.

Natalia's mother's major concerns were the fact that she does not speak English; the financial stress on the family, and the strain in the marriage due to all the changes since Natalia's diagnosis. The language barrier was resolved by utilizing a Spanish translator during team members' visits. The hospice team social worker has approached community agencies to help family with various financial needs (rent payment, utility bills, furniture, etc.). Travel for medical appointments has also been a financial strain and an additional stress. The social worker requested volunteer assistance in transporting the family to and from the Hematology/Oncology Clinic in Lexington occasionally to alleviate some of the strain. A referral to a marriage counselor was made by the social worker due to increasing problems and strain between Natalia's parents.

Natalia's siblings are of particular concern due to the fact that, in the midst of such turmoil, siblings are often 'forgotten.' The team social worker was concerned about whether Natalia's siblings were aware of their sister's prognosis and whether they had any questions. To address that concern, the team social worker made a referral to the bereavement counselor. The bereavement counselor agreed to begin visiting the family to help with anticipatory grief issues and general support as needed.

## **Bereavement Counselor**

Hospice counselors can play an integral role in assisting family members with anticipatory grief issues while the patient is still living. Assisting the family in clarifying their understanding of the



disease, aiding quality family communication, and suggesting life-enhancing family experiences can significantly improve the quality of life for all during the illness. Introducing the family to concepts of personal self-care, healthy coping strategies, support networking, and problem solving can facilitate healthy grieving for family members following the death.

In this specific case there is a large extended family living together with different developmental needs and a variety of ability levels with the English language. An art therapy exercise was utilized where the family worked on cards and a scrapbook for Natalia who was in the hospital at the time. This allowed family members of multiple generations and language abilities to participate. Family members chose pictures and wrote captions for the scrapbook and talked about Natalia as they worked. Younger children worked on cards for her. For those who spoke English, the bereavement counselor was able to talk with them about coping mechanisms, their support network, and how they were adjusting to changes within their family. A volunteer translator was also used for those family members who do not speak English. Specific goals for this particular session were to encourage increased communication within the family system, emphasize problem solving about current stressors and changes, and assist the family in identifying strategies and support they already are utilizing.

In order to provide ongoing support, the counselor continued making periodic co-visits with the team social worker and scheduling individual counseling appointments with family members needing specialized support. The bereavement counselor, assisted by a translator, spent a session with the mother who was experiencing difficulties with other adult family members and assisted her in deciding how to approach the situation. Visits with Natalia's siblings have involved counseling techniques that facilitated them sharing how they felt about their sister's illness, as well as identifying medical questions they would like answered concerning the illness. The siblings expressed a need to understand the illness and wanted more information. Their mother had not communicated this information previously because she thought it might be stressful to them. Opening up this communication between the parents and siblings of the patient was an important way to help the children feel secure that were being fully informed about the illness. The counselor assisted individual family members in evaluating how they are adjusting to the changes brought to the family by the illness. This was followed by psychoeducation and problem solving with the clients to provide them greater coping resources.

One sibling experienced nightmares and the counselor worked with the sibling, helping her to identify what the dreams meant to her and how to approach them so they are no longer frightening and disruptive to her sleep. Therapeutic techniques varied according to the developmental level of each family member. The children respond well to a variety of techniques with play therapy, art therapy, and the therapeutic use of literature. Older teens and adults in the family were more comfortable and responsive to a conversational format.

## **Chaplain**

The chaplain has visited several times with Natalia and her family, also utilizing the services of a volunteer translator. The family is affiliated with the Catholic Church in Mexico. Since they moved to a rural area of Kentucky, no Spanish speaking service has been available for them to attend in their community. The family has previously attended Spanish service at a Catholic Church in Lexington. Due to intense medical care required to treat Natalia's illness, the family



has not been to a church service in several months. The family reports the Catholic priest (from church in Lexington) visited Natalia during her initial hospitalization and diagnosis but the priest has not visited the home. The hospice and palliative care chaplain contacted the priest to collaborate on Natalia's spiritual care, as well as educating the priest about the chaplain's role in the spiritual care of the patient and family.

Natalia has been very private about sharing concerns about her illness and feelings with the chaplain, but has shared with the social worker she is afraid of 'bleeding out' on the operating table and dying. The social worker shared this with the team. A current care plan includes interventions to assist the chaplain in building trust with Natalia to facilitate the sharing of her faith and feelings. In an effort to help build rapport, the chaplain recently joined with other members of the hospice and palliative care team to celebrate Natalia's 15<sup>th</sup> birthday, which is a major celebration in their Hispanic culture.

Natalia's mom says she is utilizing her faith to pray for her daughter's cure and is very anxious and still seeking to accept the seriousness of her daughter's illness. The hospice and palliative care chaplain is supportive of Natalia's mom's hope for a cure. Her mom is very receptive to chaplain visits and open to prayer. The chaplain will continue to be available for discussion of concerns and feelings and to be supportive of Natalia and her family. The chaplain will continue to address the family's hope for recovery, assisting them to understand how their desire for hoping for cure may change. The chaplain is also facilitating conversations with Natalia's older sibling as she speaks English fluently and is very open to conversations with the chaplain.

## **Volunteers**

Natalia's family is assigned two volunteer translators. The interdisciplinary team provides ongoing support to the volunteers as they are translating sensitive information in emotionally-charged situations.

Volunteers are also providing occasional transportation from Natalia's home to the Hematology/Oncology clinic in Lexington. Again the team provides ongoing support to these volunteers.

## **Pediatric Coordinator**

The role of the Pediatric Coordinator is to manage the care of pediatric patients and provide team leadership. It is important for the team leader to motivate the team to meet the needs of patients and families and to help team members plan and problem solve. Team members may bring issues that they need assistance with to the pediatric coordinator. It is also important to offer ongoing support, promote and model effective communication, and address team conflicts which may occur.

Webster's New College Dictionary defines team work as "a cooperative effort by the members of a group to achieve a common goal" (2001). In this case the common goal is the provision of coordinated physical, psychosocial, and spiritual care to control symptoms, promote comfort, and increase quality of life for Natalia and her family. Each team member is responsible for achieving this goal.



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Interdisciplinary discussions about patient care occur both informally and informally. Informal discussions may take on a daily basis. Formal discussions take place at interdisciplinary team meetings (which meet every other week). At IDT meetings the hospice and palliative care team reviews each case; individual team members discuss issues and collaborate to update the patient's interdisciplinary plan of care.

Two issues addressed through effective teamwork are described below.

The family was upset that Natalia had previously been used as a translator for her parents. The hematology/oncology clinic was also not pleased with this situation, but was coping with the unavailability of translator. This issue was discussed at a team meeting and the idea for the current plan was generated by the volunteer medical associate. The hospice and palliative care team presented this idea to the hematology/oncology clinic and they were receptive. Thus, a plan was put in place.

Meeting the psychosocial needs of this family has been particularly challenging. Numerous family members require intervention—Natalia, her parents, siblings, and extended family. In order to offer adequate psychosocial support the social worker has requested early involvement of the bereavement counselor who is primarily addressing the psychosocial issues of the siblings, but is available to all family members as needed.

Shared decision-making and flexible leadership should also be present in effective team work. For example, the primary nurse took the leadership role in addressing the problem of the unavailability of a Spanish translator at the clinic while the social worker took a leadership role in arranging psychosocial support for Natalia's siblings and extended family. Both solutions involve team work to be effective. The primary nurse must coordinate communication with the clinic, family, and volunteer translator (when a translator is unavailable at the clinic). The nurse, social worker, and chaplain communicate frequently with the bereavement counselor regarding Natalia's condition, family changes, and issues to assist the bereavement counselor in providing appropriate psychosocial support to the siblings and extended family.

Team members are also encouraged to make co-visits when possible, not only to foster team work, but to make better use of the translators. For example, the celebration of Natalia's 15<sup>th</sup> birthday was a coordinated effort by all team members to enhance her quality of life.

One of the hallmarks of hospice and palliative care is team work. The issues of Natalia and her family are much too complex to be addressed by anyone individual or discipline. Therefore, care is best provided by an interdisciplinary team.



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## Suggested Considerations and Guidelines for Working with Seriously-Ill and Dying Teens on Legacy Activities

Ann Fitzsimons

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### Remembering this is the Dying Teen's Journey

There's an old Motown song whose refrain is "Never can say good-bye." But what happens to a dying teen when there is no other choice? How does a teen say goodbye to life and those he or she loves? How do these teens manage the tasks of dying? When elders die, most review their lives and organize their personal affairs, often expressing concerns about their legacies. How do teenagers make their mark on this earth in their short time here?

While few of us can put ourselves in the position of being a seriously-ill or dying teen, or even begin to imagine what this journey must be like for them, we can relate to the unique needs and challenges that may arise for these teens and their families at this time as they work towards completion at the end of their life. Teens, as well as adults, likely have an end-of-life "To Do" list, whether they are cognizant of it or not. And with a little urging, some teens may welcome the opportunity to have someone help provide structure to activities that will facilitate them in saying their good-byes. To begin this dialogue, it is imperative to give dying teens a voice in their own dying processes. Ask them what THEY want to do with their final days, weeks, or months for themselves, and separately, for family, friends, and others they are leaving behind.

There are two important first steps in this process. First, talk about what the teen has accomplished in his or her life, no matter what age. Exploring this with them will help them realize and take pride in what they HAVE accomplished, taking the focus away from how much more they could do or will never be able to do because they are dying. Second, encourage them to begin at a time when they feel ready to put energy into projects like these. They may need and want help from the very beginning if they are feeling wiped out from their illness or treatment, or they may just need to have seeds planted and they'll self-start, but then need help as their illness progresses and their energy waxes and wanes. Some teens and their parents understand the need to have a Plan A, Plan B, etc., while never taking away hope for recovery. Starting them on their legacy track early when they have the energy and ability to focus on these activities will be important. Beginning with some normal activities that teens do regardless of whether or not they're dying, is a good way to help a teen ease into the mindset of starting to complete his or her life review and say good-bye.

Because a teen is still in the care of his or her family, and not launched yet into the world, it is not unusual for family conflicts to arise because parents and the teen may not be at the same place in their acceptance of the teen's illness. Therefore, every effort should be made to support the teen's wishes as well as honor the parents' role as parent. Each family is unique and has its own special balance. It is important to be very sensitive to that balance. Although it may be obvious to an outsider what "should" be done to have the child's needs met, it is the



parents who must live with the decisions that are made at this time for the rest of their lives. It is a delicate balance to work with a family who is losing a child and a great honor that they have entrusted us with the important role of guide at this vulnerable time. Although the ideal goal is to focus solely on the needs of the teen at this point in their journey—to help fulfill his or her wishes, hopes, and desires for their time left—it is vital to honor the existing family dynamic as well.

## **Guidelines for Working with Dying Teens**

The following are some “guidelines” for those working with teens who are undertaking legacy-related projects or activities:

- Spend some time just “connecting” with them. Listen to what they have to say and find out who they are and what they are about.
- Meet the teens where THEY are in this emotional journey. Ask what matters to them. What do they need to do or say...and to whom? What concerns them most at this point regarding what they say to others?
- Face them squarely and on their level, maintaining good eye contact, learning slightly toward them in a relaxed manner. Enjoy them.
- Recognize that they're not kids, but not quite adults, and that their behaviors may vacillate between being child-like and wanting to be an adult. During times of stress, they may even show some signs of regression.
- Focus on an activity that takes the pressure off of them verbally as it may be difficult for them to give voice to some of what they're thinking and feeling.
- Adopt an open posture and wear clothes that set an informal and comfortable tone.
- Do not judge what you hear...or look surprised at anything they say or do.
- Use facial expressions and verbal prompts, nods, and a soothing voice tone to indicate that you are listening.
- Reflect back the feelings you hear so they will know you are listening. Don't work too hard. Be casual, but caring.
- Utilize their personal strengths and character to encourage them in their legacy work.
- Incorporate peer group support whenever possible and encourage interaction with peers from within and outside the hospital, hospice, or their home.
- Normalize and validate feelings to de-emphasize their feelings of not being “normal.”
- Encourage them to express their range of emotions with activities such as talking, writing, or drawing.
- Try and find ways to build some of these activities into the teens' normal everyday activities, where doing them doesn't seem like such a “big deal,” but is more a matter of their everyday teen life (and thus, they may be more apt to do some of them).
- Teens are especially self-conscious about their own art abilities, even if they have artistic talent, so they may need to be gently prodded a bit to do some of the activities suggested in this and the following article.
- Follow-up with them and come back to continue work on their legacy activities and projects when you say you will. Keep your promises.



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## Helping Seriously-Ill and Dying Teens Leave their Mark on their World

**Ann Fitzsimons**

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Seriously-ill and dying teens have a “Chinese menu” of legacy-activities they could potentially undertake on their own or with the help of others. However, it should be recognized that some teens may never be willing or able to do any type of legacy activities, while others may embrace many of these. The professionals, families, and caregivers working with each teen need to assess whether broaching the idea of doing such activities is in the best interest of the teen and their family. If there seems to be some receptivity on the teen’s part, then provide him or her with a range of options and let *them* select the activities that may be of interest to them. Be cognizant of your honored, but temporary, place in this family and never take a role that displaces the family or existing friends. Anytime you can empower or include the teen’s existing social supports, you are helping them as they begin their own journeys of grief. So, if they’re open, share some of these suggestions with the teen’s family and caregivers so that they can help facilitate legacy activities as a normal part of the teen’s everyday life outside the hospital or hospice setting. These may also spur some thoughts of their own as to other things they could do that would be meaningful to the teen and those who love him or her.

### Advanced Directives, Living Wills, and Ethical Wills

- Advanced Directives and Living Wills specifically written for children and teens are becoming an emerging topic in the field of hospice and palliative care. (See Article on this topic elsewhere in this Newsletter).
- The intent in developing Advanced Directives and Living Wills for children and teens is the same as for adults—to provide the teen and his or her parents a forum for stating their wishes, needs, and desires as they relate to their healthcare decision-making. The Living Will document is intended to help those who love and care for the ill or dying youngster to know what the *teen* wants if they’re unable to speak for themselves. Separately, the Advanced Directive may be drawn up by the parents *for* the dying teen so the healthcare team knows what the teen’s end-of-life wishes are, (hopefully) as supported by his or her parents.
- The Living Will may be written in first person with the teen filling in the blanks and can include a range of issues from decisions related to the teen’s physical health to wish fulfillment or legacy activities they’d like to do, to their own funeral and memorial-service planning.
- The Advanced Directive attempts to clearly state what the teen’s wishes are (as supported by the parents) for any or no procedures or interventions to be done on or for the dying teen, including CPR, airway support, mechanical breathing, pain and symptom management, visitors, nutrition and hydration, surgery, dialysis, antibiotics, transfusions, diagnostic testing, etc.
- Ethical Wills are another newly emerging legacy activity and one that is very appropriate for seriously ill or dying teens. They are a way to preserve one’s values, beliefs, hopes,



and wisdom for others in written, taped or video recordings. Barry Baines has written a wonderful book (*Ethical Wills: Putting Your Values on Paper*) and workbook (*The Ethical Will Writing Guide and Workbook: Preserving Your Legacy of Values for Your Family and Community*) on this topic. His website ([www.ethicalwill.com](http://www.ethicalwill.com)) also is a valuable resource for this activity.

## Photography, Photos, and Picture Journals

Photos and pictures are a great non-verbal way to have teens express themselves while during and near the end of their journey.

- Give the teen a disposable camera and let him or her shoot away or let others take pictures of him or her doing whatever he or she wants to have captured for posterity. Encourage the teen to have or keep a camera with him or her at all times to capture whatever catches his or her interest or to document his or her journey with family, friends, caregivers, healthcare staff, and others. Capture “A Day in the Life of Me” in photos or video, or “The World According to...”.
- Contact a local hospice or palliative care program to see if they are affiliated with any professional photographers who will come to the hospital, hospice, or youngster’s home (often free of charge to the family) and take some beautiful photos of the dying teen alone and/or with his or her family for the family to have for years to come. Remember to include siblings with a 1-on-1 photo of themselves so they don’t feel left out. Try to find a volunteer who may be a professional or skilled photographer in your organization to offer this service if a professional is not available.
- Have the teens go through old photo albums of themselves, their family, and their friends, and compile pictures from their life into a scrapbook highlighting their milestones (e.g., birthdays, middle or grade school graduations, participating in team sports, special family events like vacations, holidays, birthdays, etc.). Some scrapbook supplies and kits can be purchased at local crafting stores for a nominal fee to help get them started if they’re struggling with this activity.
- Photo collages or other collages using age-appropriate magazines can be crafted around relevant themes to the teen (e.g., Favorite Memories, All About Me, Me and my Family, etc.) and can be made on larger, poster size boards that can be kept in the ill or dying teen’s room. Importantly, these can be added to over time by the teen or visitors as his or her illness progresses. These can also serve as memorial boards for the teen at his or her funeral or memorial service, if one is held.
- Photo Journaling Templates are also being used by some hospitals and hospices involving pre-made photo journaling sheets that help the patient just insert their photos into a ready-made scrapbook page and then document or write about different experiences and reflections they have on the photos. With different sheets available when they come for treatments, the teen could have a life review (or some other themed) photo-journal or scrapbook completed during down time spent in the hospital.

## Videography

- Videography is similar to photography, except that this uses videos as the medium. Video documentation of the ill or dying teen in school events (where possible), family



functions, outings with friends, and during alone or quiet time, is another way for a teen to document that he or she is (and was) here to themselves...and to others.

- The teen may also want to make videos for individual family members or friends telling them what they've meant to him or her and recounting good times shared with the individual(s). If videotaping equipment is not available, this can also be done by the teen audiotaping messages, reflections, and thoughts to his or her loved ones.
- Making a video reflecting on one's own life (at birth, memories from childhood, other favorite memories, favorite color, favorite foods, what the teen wants people to remember about himself or herself, etc.), either unaided or using any scrapbooks or photo journals the teen has compiled as a conversation aid could also be helpful.
- Some local cable stations may also be willing to let the teen come into the studio and tape something more professional and/or they may send a cameraman to the house to tape the teen at home with family and friends or alone.

## Music

- If the teen is musical, he or she may want to record himself or herself on CDs playing a musical instrument for personal enjoyment and for others to listen to. If they play in a band or with others, record both solo and band pieces.
- If the teen is not a budding Green Day artist, then he or she may want to compile a comprehensive playlist for their IPOD or MP-3 player that is a representation of all the different types of music they like (or have liked) over time. An exhaustive list of selections will help them pass the time when ill or alone and will be something special they can leave for a loved one when they're gone to help remember them and their likes in music. Consider the individual personally narrating the songs, a sort of annotated music bibliography of music that the teen likes.

## Memory Boxes

- Boxes (any size with a lid, such as a cigar box) can be decorated and used to place a special item or items in it that the teen treasures from special people, places, and times. It doesn't matter what the items are, only that the teens get to decorate the box the way they want (or buy one pre-decorated from a craft store) and pick the items that are to go inside.
- Suggest the teen apply a handprint to the lid of the box or inside. Or affix a photo of themselves that they choose. Photo storage boxes from craft stores or Target make great memory boxes and are inexpensive.
- The family might also want to buy and fill a time capsule kit in which the entire family places mementos of a particular year or special times with the ill or dying teen, and then bury it in the yard (or someplace safe but of significance for the family like at a family cottage), to be dug up and opened at a later date, as agreed to by the teen and family.

## Memory Bracelets

- Bracelets can be made using a wide variety of beads and charms to create a wearable and memorable piece of jewelry. Teens could be guided to choose beads that represent



a special memory in their lives or about themselves or their loved ones. This activity can be done by a teen alone, or with other loved ones. After the teen and/or others have made their bracelets, they may want to have each person explain the meaning of their bracelet...what beads they picked to signify which memories with the ill or dying teen...and why.

- Pre-made memory bracelets can also be purchased at some craft and specialty stores. These are like charm bracelets that allow for small pictures of special people, places, pets, or things to be inserted into the charms.

## Creative Art-Related Projects

- Poetry
  - For those teens so inclined, poetry offers a soulful outlet of self-expression as they face their hopes, fears, limitations, and so much more that has been brought on by their illness. Writing prose or poetry may be a way to process some of what they're going through, regardless of whether it is shared with others or not. Consider having them do an audio version of their favorite writings, thoughts, or musings.
- Creative Writing/Journaling
  - Creative writing or journaling can help teens focus inward and identify their feelings within a "safe place" in which these feelings and emotions can be expressed. When they write just for themselves, they can begin to process and hopefully heal parts of themselves on this journey. It will be up to them as to whether they want the journal read by others upon their passing, or destroyed. Whichever they choose, their wishes should be honored.
  - To help get the teens started, provide a journal that you think will appeal to them or have them select one of their own liking. Encourage them to find a good time and place to map out as their own for this activity. Once they get started, they may want to have their journal with them throughout the day to jot down different thoughts, feelings, or emotions as they pop up. Just guide them to write down the first thing that comes to mind. Let their thoughts flow and to keep writing until their mind is emptied. Then have them date their journal as a reference point when they go back and reflect on their thoughts at later points in time.
  - Journaling might also be aided for teens having trouble getting started by comprising some templates or mini journals with some fill-in-the blanks to help them on their way. For example:
    - My Favorite Things. Make a fill-in-the blanks journal of their
    - Favorite Things (e.g., Favorite place to eat out, Favorite food, Favorite movie, Favorite song, Favorite vacation, Favorite color, Favorite hobby, etc.)
    - All About Me: Make a fill-in-the-blank journal in which the
    - teen can write about himself or herself for either their own or public eyes. This might include having them list their greatest personal achievement up to this point in their life, one (or more) things they've done that they've been proud of, what dreams or aspirations they have, what makes them laugh, If they won a \$1,000, they would..., etc.
    - Ref: *The Creative Journal: A Handbook for Teens* by Lucia Capacchoione



- Letters to a Loved One
  - If the teen hasn't videotaped or audiotaped any messages to their loved ones, suggest they write a letter to whomever they want to. The teen may not need any prompting, but if they do, suggest they write to the person about how much they care for them, memories they cherish with them, or to explain things they wish had been different between them. You might be able to help the teen write the letters if they are not able to themselves.
- Website, Web pages, and Care pages
  - Many of the above written activities can be created or incorporated into a teen's own web page. There are Care Pages, but there could also be some writing applications as well as interactive poetry and art that is posted there that teens might get into and that would encourage peer participation.
- Painting
  - This could involve something as simple as a dying teen painting their handprints on white paper with another loved one's handprint overlaid on theirs in paint, to doing spin art and using colors to express themselves, to painting actual pictures of whatever is in their hearts and heads.
- Sculpting with clay
  - Sometimes teens don't want to talk about what they're going through. If so, having them make something from clay is a good tool for helping them release pent-up energy or anger, while making something that will last. They can push, pull, and pound on the clay to release anything they're feeling (good or bad) and then create a symbol that stands for them or something important to them in their lives.

## Bequeathing Favorite Things

- Have the teen develop a list of some of their favorite or special things that they want others (e.g., parents, siblings, friends, etc.) to have. This may be done by them actually giving some of these things away to others while they're still living; verbally by telling a sibling, for example, that he or she can have his I-POD when they're no longer able to use it; or by putting it in writing, to be read after they have died. If they're able and up for it, they may want to write notes to the recipients to accompany the item explaining why they're giving this to them and its significance to them in their life.

## Legacy Activities for Peers and Siblings Left Behind

When dying teens do not want to undertake legacy work, this has to be honored. However, you may then want to consider working with peer teens and their siblings after the teen's death in some legacy-related activities to aid them in their grief work. Legacy work can be done long after a death and sometimes helps, especially if complicated grief is apparent. Even at this point in the process, the peers and siblings may find undertaking such activities to be a powerful way to make meaning out of their loss. Many of the activities that surviving teen peers and siblings could do as meaning-making after death are similar to those outlined in this article. Others might include collecting or retrieving a personal object from the dying teen's belongings; creating a box, or quilt, or mosaic, something special to remember the person by; conducting an annual memorial or celebration, etc. Sometimes legacy work can take on a life of its own and



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may be more comfortable or inspirational to teens after the death of their loved one or peer. This is especially apparent in schoolmates and church or activity groups that the teen was part of. Art therapy sessions can be helpful during phases where they are going “back” to commemorate their loved one if those activities did not take place during active dying, if supported and kept in the context of grief work.

In closing, in our personal lives and in our professional work with seriously-ill and dying teens and their families, I'd like to share a meaningful quote of relevance to me and this topic:

*“Do all you can with what you have, in the time you have, in the place you are.”*  
-Nkosi Johnson, 12-year-old deceased AIDS Activist

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