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## Providing pediatric patients with a voice : understanding how children want to live before they die

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# Providing Pediatric Patients with A Voice:

Understanding How Children Want To Live Before They Die

By

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Mentor:

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Submitted in partial fulfillment of the requirements of the degree of  
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*“So let that be a lesson to one and to all; a person is a person, no matter how small”*  
— *Dr. Seuss, Horton Hears a Who! (1954)*

*“You treat a disease you win, you lose.*  
*You treat a person, I guarantee you, you'll win, no matter the outcome.”*  
- *Patch Adams (1998)*

**ABSTRACT**

At present, there is no literature that defines what quality of life means for a child. The following paper explores what quality of life is for pediatric patients and how health care professionals, a certified child life specialist in particular, can help the patient, family, and medical team to navigate treatment options and decisions regarding end-of-life. Palliative care is an all-inclusive approach that requires the coordinated efforts of a multidisciplinary group of caregivers to treat the physical and psychosocial needs of patients and their families. Early introduction of palliative care principles and practices into a child's treatment that are respectful and supportive of the goals of that individual child can frame the transition to end-of-life in a way that maintains the integrity of the child. Currently, children are not legally classified to make healthcare decisions regarding their own bodies. Through a child life specialist's understanding and training in child development, a child's cognitive ability for decision-making capacity can provide a viewpoint from the lense of a chronically or terminally ill child.

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## INTRODUCTION

Dr. Rodney Syme is the Vice President of Dying With Dignity, an Australian based organization that strives for dignity at the end-of-life. Symes has written numerous journals and articles that all state that “giving people control over the end of their lives is one of the most valuable palliative tools we have at our disposal” (Syme 2015). In the United States, minors are seldomly active participants in decisions regarding their healthcare, especially in regards to end-of-life decisions. “Until a person has come to terms with their own mortality, everyone wants to bury their head in the sand” stated Joy Deanna Howell, MD, a pediatric critical care attending at New York Presbyterian Hospital Weill Cornell Medical Center. The World Health Organization (WHO) defines quality of life as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” The individual’s perception is affected by “physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (World Health Organization, 1997). The definition WHO provided for quality of life in 1997 is likely referring to the quality of life for adults. How would “physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” be defined for or by a child? Children are often deprived of their voices either physically or by law, leaving caregivers to make their decisions for them. By using the above definition adapted to what is important to children with chronic illness a framework is offered that includes them in conversations about their own care, what goals are

important to them and how they would like to be cared for throughout their treatment and at the end-of-life.

Decisions made by the medical team and the child's family may not take into consideration what that individual child might have to say about the choices that are being made on his or her behalf. Dr. Jutte van der Werff Ten Bosch is a pediatric oncologist at Brussels University Hospital. Van der Werff Ten Bosch writes that "children at the end of life experience the same symptoms as dying adults — respiratory distress, muscle wasting, nausea and vomiting, fatigue and weakness, problems swallowing, anxiety and distress" (Kirkey, 2016). When a child is suffering from the aforementioned symptoms, he or she misses social and developmental milestones, falls behind in school, and is often reluctant to play with toys or peers. Who and what defines quality of life for a child may have ethical implications for families and healthcare professionals. Research on the topic has made it clear that the best case scenario for a child's end-of-life is a team that consists of the child, the family, and a diverse array of medical professionals.

To ensure that the best decisions are made for children and adolescents, these decisions should be made jointly by members of the health care team, the child or adolescent's parents, and sometimes the child or adolescent. Children and adolescents should be involved in decision-making to an increasing degree as they develop, until they are capable of making their own decisions about treatment. End-of-life decision-making, whether or not the child or adolescent is involved, is especially complex (Harrison, 2004.)

Traditionally, the family and the medical team make decisions for pediatric patients (Rogers et al. 2009), due to the belief that children do not have the capacity to developmentally understand treatment and/or end-of-life options. This belief corresponds to the legal view of children's decision making ability. Hilden et al. writes that "historically, children have been declared legally and ethically incompetent to participate in decisions about their own health care" (2001).

Quality of life as defined by the WHO incorporates criteria based on an adult's perception of his position in life and how it is affected. The first listed criterion is an individual's physical health. The Indiana Institute on Disability and Community define physical well-being as the "ability to be fully engaged, on a regular basis, in all developmentally appropriate activities" (2006). Disruption in full engagement "can have a negative impact on the attainment of the breadth and complexity of skills" (Indiana Institute on Disability and Community, 2006). In an adult, "developmentally appropriate" activities may be going to work, fulfilling family obligations, engaging in activities and hobbies that bring pleasure. When applying this same concept of "developmentally appropriate activities" for children one must consider the work of the child; school, play, and engagement with family and peers (Child Development Institute 2015). An inability to participate and obtain skills that are frequently accomplished by healthy peers can affect a child's sense of industry and self-worth. Despite the fact that an ill child may simply feel sick, a child with a serious illness is often unable to develop properly due to missed opportunities for growth and education both academically and socially. Pediatric patients have very few choices in their lives. When they can eat, sleep, and even play revolves around their medical schedules. A child's physical health frames opportunities to learn by either broadening

them or narrowing them. Like an adult, a child's physical health affects many aspects of life, however the disruption of play, learning and hindrance to growth is unique to the declining physical health of a seriously ill child.

“A child's physical well-being can affect the ability to actively engage, physically and mentally, in the intended and unintended learning opportunities” (Indiana Institute on Disability and Community, 2006). Paramount to the disruption of a child's learning is the ill child's inability or lack of desire to play. For children, play is “a pathway for personal expression and growth, a means for gaining emotional insight and resolving conflict” (Franklin, 2000). Without the ability or interest to play would a child be “fully engaged in developmentally appropriate activities” and according to the definition of the WHO experiencing quality of life?

The second criteria listed by the WHO is a person's psychological state. Factors that contribute to an individual's perception of quality of life based on psychological state are; social, emotional, and cognitive factors. Unlike adults, “children and adolescents are still in a period of social development which involves learning the values, knowledge and skills that enable them to relate to others” (The Royal Children's Hospital Melbourne 2016). Adults tend to have a defined and stable understanding of their values, behaviour, and social circles where children pick up cues from the world around them to aid in development. “Children and adolescents are still developing their ability to recognize and manage their emotions or feelings, and this can be influenced by many social and environmental factors” (The Royal Children's Hospital Melbourne, 2016). For example, the emotional bond or ‘attachment’ that infants and young children experience with their caregivers is central to their emotional development. The disruption of the bonding process due to frequent medical procedures, isolation, and illness may

result in “separation anxiety which is emotional distress” (The Royal Children's Hospital Melbourne, 2016). The impact of negative influences such as hospitalization also shapes social behaviours and interactions with other people that can all affect a child’s psychological state. Chronically ill children whose school is disrupted by frequent medical visits and long term hospitalizations experience developmental delays socially, emotionally and cognitively. “It is really peer relationships that are a core catalyst for the psychosocial development of the school-age child. Children’s identity and sense of competence begin to be developed largely through a process of comparison with their peers” (Ernst, Johnson & Stark 2011). Chronically ill children often face stigma and are considered less desirable friends than healthy peers. It is written in *The Handbook of Pediatric Psychology in School Settings* that “social opportunities for chronically ill children can be affected by peers’ fears and misconceptions about the illness... Children may fear that it is contagious and respond by avoiding, teasing, or rejecting chronically ill children” (Shapiro & Manz 2008, p.51). Towards end-of-life, children are often isolated, unable to play, or attend school; which all impact a child’s psychological state. Fear of abandonment and isolation, especially during a child's long illness, is a major concern to chronically ill or dying children and their families (American Academy of Pediatrics 2000). According to the WHO definition, chronic illness that leads to a poor psychological state can correlate with a poor quality of life.

An individual’s level of independence is the third measure of a person’s perception of their position in life. To achieve independence from one’s parents is a hallmark of growth and maturity. From the moment a child is born there is a slow yet steady incline from dependence to independence. Erik Erikson’s lifespan model of development has five stages that range from

birth to eighteen years. According to Erikson's theory, the psychological hurdles of development that require a sense of mastery are autonomy, initiative, industry, and identity. From as early as eighteen months, children can begin to develop their independence from picking which toy to play with, walking away from their caregiver, making choices about the clothing they like to wear and what foods they like to eat, to going to college, getting a job and being able to care for oneself and a family. Autonomy, initiative, industry, and identity are all crucial components of independence. Most adult patients at their end-of-life, will become dependent on those around them for the completion of simple tasks like bathing and dressing. This is often seen as a burden on the family and a position no healthy adult wants to be in. Being cared for by one's loved ones as an adult is seen as a step backwards developmentally and the dying adult may experience shame, guilt, and embarrassment. Not only will children of all ages become more dependent as their health declines, they may also experience developmental regression (National Institute of Health, 2011). Developmental regression such as wetting the bed, sleeping with a stuffed animal, and verbal regression can sometimes manifest due to "a personal fight by children to take control of their environment" (National Institute of Health, 2011). Children who have made steps towards independence as seen by a preschool age child who is toilet trained, a school age child who can walk home from school by themselves or an adolescent who has learned to drive does not want to give up this independence. For instance, "dying teenagers often become upset at their dependence on caregivers and family at a time when independence and peers are of paramount importance" (Lewis et al. 2005). Being bedridden and dependent on caregivers leads to embarrassment, shame, and often guilt in the chronically ill child similar to that of the adult. "Dependency is often associated with negative feelings, powerlessness, frailty, and

vulnerability...Dependency thus contributes to making life frail” (Henriksen & Vetlesen, 2000). However, in an adult we consider this a sign of poor quality of life as we can imagine ourselves being in this position. When it is a child, caregivers assume this role as part of their parenting responsibility with little regard or understanding of the impact on a child’s independence and what that means to him. A child’s independence is further decreased when an illness affects a child’s ability to explore and use motor skills. When a child is ill, their initiative may be discouraged by parents who feel the need to be overprotective and may be reluctant to set limits or foster a sense of independence in their child. The desire for independence is most urgent for the adolescent patient who must grapple with decreasing independence as the independence of their healthier peers increases as well as societal pressure to move away from one’s caregivers and form an independent identity of self.

When a child is routinely hospitalized, he is stripped of the ability to make decisions thereby limiting his independence. The majority of non hospitalized children’s time is structured by a schedule that dictates times for eating, dressing, going to school, playing, and sleeping. This loss of routine can be distressing for the hospitalized child and is “often demonstrated in problems with activities such as eating, sleeping, dressing, bathing, toileting, and social interaction” (Sanders 2011, p. 977). Hospitalized children are told what to wear, what and usually when to eat, and are rarely in control of the timing and placement of frequent medical interventions. When a child is at the end-of-life, the sense of a lack of control is heightened as the patient is often confined to a bed and may have limited ability to control body functioning.

Social relationships are the fourth principle that affect an individual’s perception of self.

The 2004 Institute of Medicine report *Children's Health, the Nation's Wealth* defined children’s

health as the extent to which a child is “able to (a) develop and realize their potential, (b) satisfy their needs, and (c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.” A very young child may be aware of siblings and peers that are able to partake in activities for play and education that require a level of time and energy that is not afforded to pediatric patients. A child’s social relationships are largely dependent on age and development. For instance, young children’s relationships revolve around immediate family members. As typically developing children grow, so too do their social circles and their depth of social relationships outside the home. When a child reaches adolescence, there is a greater emphasis on social relationships that become important for identity and independence. A chronically ill child may experience a decrease in his ability to cultivate relationships in school or within the community as his disease worsens. The relationships that become central to the hospitalized child are those that are formed with the health care team and other hospitalized children. The goal for children and adolescents is “to build a positive sense of their own identity and their role in relationships with people around them” (The Royal Children’s Hospital Melbourne, 2016). The sense of identity for a hospitalized child greatly differs from the identity of a healthier peer. The healthy peer may identify himself by his environment, activity, and/or the company he keeps: a good student, friend or soccer player. A chronically ill child will do the same; only for the child with chronic illness his identity relates to his diagnosis and prognosis of disease, framing him as patient first and child second. This distinction may also create a rift between children as experiences are not shared or clearly understood by each other limiting the child’s perception of self to realize potential, satisfy needs, and allow the child to interact with environments and peers.

The fifth and final component of how an individual's perception is affected is by "personal beliefs and their relationship to salient features of their environment" (World Health Organization, 1997). A child's personal beliefs are largely dependent on the culture and value system of their family. The environments of ill children are often limited to the health care setting and their homes which restricts them from many activities that are part of a *normal* child's daily life such as attending school and playing with friends outside of the home. S. Claire Selzer, in her contributions to *Behavioral Pediatrics*, wrote that "there is evidence that the normal development of the central nervous system...depends to some degree on the nature and timing of early experiences that can serve to facilitate or impede development" (2003, p.11). There are many different facets of a child's environment that affect development that range from the home to extensive cultural and social settings. However it is the child's immediate environment which largely includes the central role of the child's family that exerts the most influence on development. "The child's access to stimulating and educating materials is an important aspect of the immediate environment" (Selzer 2003, p. 11). A child that is isolated and not stimulated is in jeopardy of forming limited relationships and thereby having limited experiences. It is important for the chronically ill child to be exposed to as much as possible in order to facilitate a relationship to the environment that is reasonable in the eyes of that child.

### **INCORPORATING THE NEW PALLIATIVE CARE MODEL**

In order to best support children and families affected by life limiting illness it is important to assess the palliative care model and the influence on families perceptions of medical treatment from diagnosis to end-of-life. The American Academy of Pediatrics defines palliative care as a "multidisciplinary approach to specialized medical care for people with

serious illnesses” (AAP, 2016). Palliative care provides patients with relief from the symptoms, pain, physical stress, and mental stress by focusing on “pain and symptom management, information sharing and advance care planning, practical, psychosocial and spiritual support, and coordination of care (AAP, 2016). Palliative care recognizes that the entire family unit often suffers along with the patient. Therefore, the focus of pediatric palliative care is to “enhance the quality of life for all involved, in large part by preventing and alleviating suffering using the skills and knowledge of a specialized care team that includes doctors, nurses, social workers, chaplains, child life therapists, and others” (AAP, 2016).

Over the past few years the palliative care model has begun to evolve around the world. Originally, palliative care was introduced at the termination of medical treatment. It was viewed as comfort care that was synonymous to hospice care and represented the onset of end-of-life. The palliative care model of today is much different. Palliative care is now introduced at the first admission or the beginning of illness and works in conjunction with medical treatment (see Figure 1).

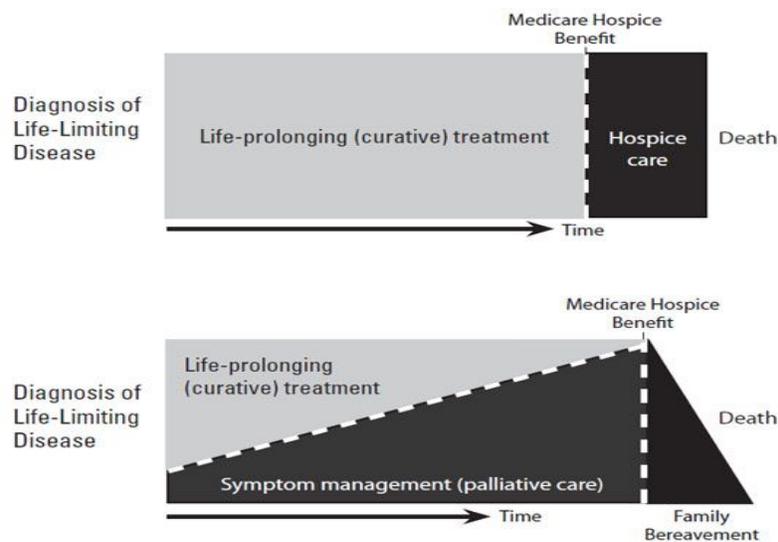


Figure 1. The Older “Transition” Model of Care Versus a “Trajectory” Model

At a conference on the new “trajectory” model of care at Morgan Stanley Children’s Hospital, Dr. Elijah Walden discussed how patients and their families tend to panic when they hear the words “palliative care” because they associate it with end-of-life. Walden and other palliative care professionals have pushed to redefine what palliative care means in the minds of healthcare professionals and the general public. It must be explained to families with the utmost sensitivity and understanding due to the potential misunderstanding that palliative care is often confused with end-of-life treatment. Child life, as part of the palliative care team, can reassure families that the presence of palliative care is not in lieu of curative treatment but functions alongside treatment to care for the family as a whole throughout the duration of medical treatment. Introducing palliative care at the onset of diagnosis can be fundamental to maintaining dignity by attempting “to understand a patient’s unique perspectives on what gives life meaning in a setting replete with depersonalizing devices” (Cook & Rocker, 2014

## **CHILD LIFE**

Gaynard et al. describes the role of the child life specialist (CCLS) as akin to a “buffer” (Gaynard et al. 1990, p. 22). “Communication across differing chronological ages, developmental levels, and decisionmaking capacities is a complex skill set to acquire and demanding to maintain” (Hilden et al. 2001). From as early as the admission process, the child life specialist acts as a liaison between the family and the culture of the medical environment. The Child Life Council defines the role of a child life specialist as

Child life specialists are trained in child development and family systems. Child life specialists promote effective coping through play, preparation, education, and self-expression activities. They provide emotional support for families, and encourage

optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization. Because they understand that a child's well being depends on the support of the family, child life specialists provide information, support and guidance to parents, siblings, and other family members (2016).

Understanding play is an integral component of assessing the quality of life for a child. At every step of the way, the child life specialist is there to ease the process and attempt to avoid the trauma that can come with pain, fear and uncertainty. "Children need play like they need air to breathe, no matter what their circumstances. Play is fundamental to the very structure and meaning of childhood. This is true even in the most onerous of circumstances, perhaps especially in times of great distress (Thompson 2009, p. 4).

Physician, educator, and innovator Maria Montessori, famously said that play is the work of the child. Play is the language of children and how children communicate fears, concerns, understanding, worries, and desires. When children engage in play the stimulation influences "the pattern of the connections made between the nerve cells. This process influences the development of fine and gross motor skills, language, socialization, personal awareness, emotional well-being, creativity, problem solving and learning ability" (Child Development Institute 2015). Child life specialists, "embrace the value of play as a healing modality and work to enhance the optimal growth and development of infants, children and youth through assessment, intervention, prevention, advocacy, and education" (The Official Documents Of The Child Life Council 2002, p. 1). Therefore the child life specialist's understanding of the need for play as an essential aspect of childhood directly correlates to the definition provided by the WHO criteria for quality of life; "individuals' perception of his position in life in the context of

the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” A child life specialist is well trained and professionally equipped to advocate for and represent the voice of a child as important decisions need to be made in regards to treatment and end-of-life.

Child life specialists are trained professionals that understand death and dying from a developmental perspective. *The Handbook of Child Life* asserts that “child life specialists may play a critical role in assessing and meeting the needs of a child or adolescent making end of life decisions” (Thompson 2009, p. 230). As advocates for their patients, a CCLS can shine a light on the child’s medical preferences and can ascertain how much and in what aspects the child wants to be involved in his care to the medical team. In addition to emotionally supporting the patient and his or her family and acting as a liaison between the family and the medical team, a CCLS can advocate for the well-being of that child. Belinda Sweett, CCLS, writes that the tenets of advocacy are “voice, rights, inclusion, and knowledge” (Anthology of Focus 2009, p.25). In her article “Advocacy and its Place in Child Life Work,” Sweett makes it clear that advocating for children is an occupational obligation.

With communication skills that incorporate the language of play, together with an understanding of development and children’s response to stress, child life specialists have both an ethical responsibility and the competency to help children make their voices heard, where others may fail to do so (Anthology of Focus 2009, p.27).

In the profession of child life, children are recognized as contributors to their health care and not passive participants. “As advocates for children, youth and families, child life specialists

must be able to recognize, evaluate and take appropriate action in the face of ethical issues related to care” (Making Ethical Decisions in Child Life Practice 2000, p.3).

In order to support a child that is facing his or her own mortality, one must understand that a child’s conception of death is fragmented into three pieces (Speece & Brent, 1996). The first piece is the concept of irreversibility, the understanding that “once something is dead it will not come alive again” (Rollins, 2005, p. 228). The second is non-functionality, the understanding that “all external and internal function have stopped” (Rollins, 2005, p. 228). The third concept is universality, the understanding that “all living things eventually die” (Rollins, 2005, p. 228). Children that have spent years in the medical system usually have a more developed concept of death than their healthier peers. A study done in 1996 showed that children with leukemia demonstrated a better understanding of irreversibility and non-functionality than children interviewed in the healthy group” (Clunies-Ross & Altmaier). Lev Vygotsky, a developmental theorist and psychologist, believed that human development is influenced by an individual’s culture. For many chronically ill children, the culture they are most exposed to is the culture that exists within a hospital. Toni L Crowell, MS, CCLS addresses the subject of children’s awareness of their own mortality in her article “Death Awareness and the Child with a Life-Threatening Illness: A Sociocultural Analysis.” She poignantly makes the observation that “like children growing up in war zones or amid extreme community violence, the child with a life-threatening illness is simply exposed to more actual instances of death” (Anthology of Focus 2009, p. 75). As professionals that can serve as a family's emotional guide through the hospital experience, a CCLS may have a very important role in implementing therapeutic play and interventions that help children and their families to

cope with and process the deaths of those around them, especially when discussing their own end-of-life choices. Sharon Granville, MS, CCLS, CTRS, NCC is the director of the Child Life Department at New York Presbyterian Hospital Weill Cornell Medical Center. Granville says that conversations about end-of-life are an ongoing process. She referenced a metaphor that is used in the documentary, *A Lion in the House* that compares the conversations to a door that opens a little bit at a time. “It can open and close many times, our role as a CCLS is to be there ready to listen when it opens, even if it’s just a crack” (2016).

Myra Bluebond-Langner has done extensive research that provides insight into how children learn about their illness, treatment, and prognosis. Bluebond-Langner discovered that children acquire knowledge about the progress of their disease in stages that have no correlation to chronological age. As children pass through each stage of understanding, they simultaneously pass through stages that relate to their own concept of self. Bluebond-Langner charted the acquisition of knowledge and the corresponding stages on a continuum that is displayed in Figure 2. At every point on this continuum there is a “catalytic” experience or event that occurs for the chronologically ill child.

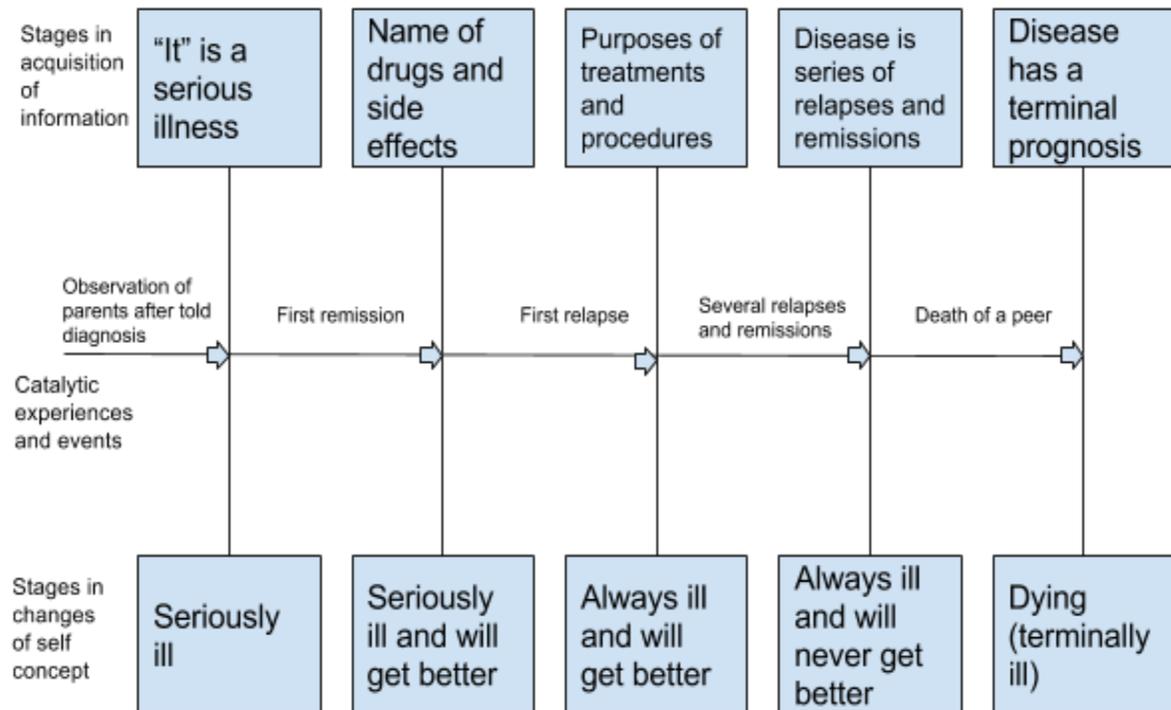


Figure 2. Children acquire knowledge of their disease process, treatment, and prognosis in stages

Child and adolescent psychiatrist Dora Black writes that “there is evidence that children, even young ones, are usually aware that they are dying” (Black, 1998). Black suggests that children pick up cues from parents and hospital staff that further contribute to the knowledge of their own mortality. Black believes that the psychological well being of families fare better when there is open communication. “The refusal of parents and medical carers to talk about issues of death and dying with children who have life threatening diseases impedes coping for the whole family” (Black, 1998). It is not easy to talk about death or visualize what it will be like when the time comes. The hardest part for many people is the sense that this is something that is completely out of their control. “As professionals we must try to change and shape this framework so that the end is something we have an influence on” said Granville. Granville explains how emotional well being in itself is something that can be controlled. “It is

our duty to do what we can to protect that well being and give families and patients some control in what usually feels like a very out of control situation” Granville 2016).

### **CASE STUDY: JULIANNA SNOW**

In 2012 two year old Julianna Snow was diagnosed with Charcot-Marie-Tooth disease (CMT), a neurodegenerative illness that currently has no cure. CMT first weakened Julianna’s arms and legs before it began to attack the nerves that control her breathing muscles. By the time Julianna was four she had lost the ability to walk, eat, hold a small toy in her hand without assistance, and cough which caused mucus to settle in her lungs causing pneumonia. It was becoming harder and harder for Julianna to breath. To assure that she was receiving the nutrition she needed, a feeding tube was placed in her stomach. Every time she got an infection she was rushed to the hospital where she was loaded with fluids and antibiotics. Another component of her treatment regimen was nasotracheal suctioning which is when a tube is placed down her nose and throat, past her gag reflex and into her lungs to suck the mucus out of the tiny pockets in her airways. Julianna was too weak to be sedated for this procedure so she was fully conscious for the entire process, every time. After each hospital admission due to deadly pneumonia, Julianna’s doctors informed her parents that they would be less likely to revive her each time. Ultimately, on one of their next visits to the hospital, she would end up sedated and on a respirator.

Julianna’s mother, Michelle Moon, is a neurologist and writer who has taken to documenting conversations with her daughter and blogging about her experience as a mother with a terminally ill daughter on her website, juliannayuri.com. Julianna’s story went viral when she published a conversation that she had with her daughter in 2014. From this

conversation and numerous other conversations with their four year old daughter, Michelle Moon and her husband Steve Snow made the decision to begin at-home hospice for their daughter. The following is an excerpt from Michelle Moon's blog:

Tears started rolling down my face, and I was glad that the room was dark. We had taught Julianna our belief that there is a better place for her. In heaven, she will be able to walk, jump and play. She will not need machines to help her breathe, and she will be able to eat real food. There will be no hospitals. Very clearly, my 4-year-old daughter was telling me that getting more time at home with her family was not worth the pain of going to the hospital again. I made sure she understood that going to heaven meant dying and leaving this Earth. And I told her that it also meant leaving her family for a while, but we would join her later. Did she still want to skip the hospital and go to heaven? She did.

Michelle believed that "Julianna's wishes were too clear to ignore" (Moon, 2015). The original conversation that Michelle had with her daughter took place in bed one night before Julianna fell asleep. The following is a transcript of this conversation:

*Julianna: Mom, do you want me to get a shot?*

Me: It depends. If you need the shot...

*J: Do you want me to go the hospital and get a shot?*

M: You don't want to go to the hospital, right, J?

*J: I don't like NT [nasotracheal suction, the thing she hated the most from the hospital].*

M: I know. So if you get sick again, you want to stay home?

*J: I hate NT. I hate the hospital.*

M: Right. So if you get sick again, you want to stay home. But you know that probably means you will go to heaven, right?

*J: (nods)*

M: And it probably means that you will go to heaven by yourself, and Mommy will join you later.

*J: But I won't be alone.*

M: That's right. You will *not* be alone.

*J: Do some people go to heaven soon?*

M: Yes. We just don't know when we go to heaven. Sometimes babies go to heaven. Sometimes really old people go to heaven.

*J: Will Alex [her 6-year-old brother] go to heaven with me?*

M: Probably not. Sometimes people go to heaven together at the same time, but most of the time, they go alone. Does that scare you?

*J: No, heaven is good. But I don't like dying.*

M: I know. That's the hard part. We don't have to be afraid of dying because we believe we go to heaven. But it's sad because I will miss you so much.

*J: Don't worry, I won't be alone.*

M: I know. I love you.

*J: Madly.*

M: Yes, I love you madly. I'm so lucky.

*J: And I'm so lucky.*

M: Why?

*J: Because you love me madly.*

Through open and honest communication with her daughter, Michelle Moon recognized that her daughter had an opinion about her treatment and about her life. She not only gave her daughter a voice, but chose to respect her decision and honor her wishes. There has been heated debate and backlash over Julianna's case. Art Caplan is a bioethicist that has read through Michelle's blogs and believes that she made the wrong decision. "I think there's zero chance a 4-year-old can understand the concept of death. That kind of thinking doesn't really develop until around age 9 or 10" Caplan said in a statement in a CNN interview in 2015. He believes that Julianna's parents put "too much stock" in what Julianna had to say about end-of-life decisions. Dr. Chris Feudtner is a pediatrician and ethicist at Children's Hospital of Philadelphia. While working at this hospital he has asked terminally ill children

that are Julianna's age what they want in regards to end-of-life decisions and has taken their feedback into consideration in appropriate circumstances. Feudtner is the chairman of the American Academy of Pediatrics section on hospice and palliative medicine. He has also read Michelle's blogs about Julianna and believes that her parents made the right decision. He found her choice for heaven over the hospital to be clear and reasonable. "Palliative care isn't about giving up. It's about choosing how you want to live before you die," he says. "This little girl has chosen how she wants to live" (Cohen, 2015).

### **A TABOO TOPIC**

"If we as a culture can acknowledge death as a fact of life, there could be less of a stigma against talking about it and planning for it" (Howell 2016). For Julianna Snow, her mother is her advocate. Her mother presented the choice between heaven and the hospital in an age appropriate and neutral way. Michelle Moon attributes part of her ability to give her daughter a voice to the honesty of her medical team. Dr. Howell made the powerful statement that to not be honest with a patient or family is "flagrant dereliction of duty" (2016). Julianna's doctor, Sarah Green told her parents that "There was no right or wrong answer. The choice was up to them" (Cohen, 2016). A new study at Boston's Dana-Farber Cancer Institute has discovered that in instances where a child is in extreme pain and fighting a terminal illness, some parents would actually choose death over life for their suffering child. The feelings of parents reported in this research are thoughts that most parents would never want to say out loud for fear of judgement. Patricia Loder is the executive director of Compassionate Friends, a national organization that supports families after the death of a child. Loder acknowledges that "a parent doesn't even want to share with other parents because society

doesn't allow you to talk about something like that" (Pfeiffer, 2010). In an interview, Loder discussed the social taboo parents of terminally ill children face. "That taboo causes some people to think, 'You're a parent and why on earth would you want your child to die?' Even though you're watching them in such distress and such pain and such agony'" (2010).

Researchers at Dana-Farber note that that these emotions are likely under-reported because many parents do not want to admit the feelings they have when they are slowly watching their child die from a terminal illness. Dr. Joanne Wolfe is the study's senior author and the director of pediatric palliative care at Dana-Farber Children's Hospital Boston. Wolfe recognizes the need to have the conversation even though society may not want to have it. "The reality is that because it's so tragic to face the loss of a child, most people don't actually want to read about it in a newspaper, they don't want to talk about it" (Pfeiffer, 2010). Wolfe goes on to say that many physicians are hesitant to have conversations about the death of a child with their parents. Loder and Wolfe agree that it is in these difficult times when parents need honesty the most. When a child's care changes from curative to solely comfort, "parents need somebody to talk to, somebody to reason with them, somebody to tell them exactly what's going to happen" (Pfeiffer, 2010).

The American Academy of Pediatrics writes that "children "have a right to be treated as developing persons, as persons with a developing capacity for rationality, autonomy, and participation in health-care decision making" (1995). A crucial component of child life is to "promote family-centered care by providing information, advocacy, and support to families of pediatric patients" (The Child Life Council, 2016). Certified Child life specialists (CCLS) are a resource for the patient, the parents, and the medical team. A certified child life specialist is

perhaps the most appropriate and ideal professional to advocate for a terminally ill child. Equipped with the understanding of children's development and the effects that chronic hospitalization and illness have on a child, a CCLS not only helps the family identify what is important to them but a CCLS can also act as liaison between child and family and the medical team to share those goals. When curative treatment is no longer reaching the goals of that individual child, a CCLS can help the family make the transition from curative care to solely comfort care. As part of the palliative care team, the CCLS eases the transitions that occur throughout treatment by utilizing palliative care concepts throughout the course of treatment. By understanding the impact and changes of language from curative to comfort, identifying and supporting family losses throughout treatment, and continuously identifying family goals both personal and medical leads to a gradual process that helps the family adjust to the reality of their situation and plan accordingly for the future. A child life specialist trained in child development, expressive arts, and coping is an ideal person to include in difficult conversations with parents and children-as part of the palliative and healthcare team.

When these conversations begin to take place is of paramount importance to this process. Some believe that the initiation of palliative care is a point of transition that is "somewhat arbitrary and lacks a universally accepted definition" (Hilden et al. 2001). However most of the literature supports the AAP's integrated model of palliative care where the components of palliative care are "offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death" (AAP 2000). Baker et al. writes that "the end-of-life care process includes care of the imminently dying patient and the patient's family but should be implemented well before death is imminent" (2008). A study

done in 2000 found that the parents of terminally ill children described their children as “peaceful and calm during their last month of life if their hospice care decision occurred earlier in the course of their illness” (Wolfe et al., 2000).

### **MY WISHES & VOICING MY CHOICES: A PLANNING GUIDE**

In order to achieve mastery and control over their own dying, children need to participate in such discussions and decisions to the fullest extent possible. Like adults, “children have grief work to do and goodbyes to say” (Hilden et al. 2001). Aging with Dignity is a national non-profit organization. Their mission statement is to “safeguard the human dignity of people as they age or face serious illness” (2016). With the help of national experts, Aging with Dignity has published two resources specifically aimed to help pediatric patients and adolescent patients navigate how they want to be cared for and to determine what is important to them at the end-of-life. “Both documents are the nation’s first tools that allow youth living with life-limiting illness to express and share their preferences for how they wish to be cared for and remembered” (Aging with Dignity 2016). These documents function as a non-legally binding advanced directive that is catered to the needs of younger patients by using developmentally appropriate language, medical terms, and themes.

Dr. Mary Ottolini is Vice Chair of Education for Children's National and a Professor of Pediatrics at the George Washington University School of Medicine and Health Sciences. Dr. Christina K. Ullrich is an Assistant Professor of Pediatrics at Harvard Medical School and a Attending Physician of Pediatric Oncology at Dana-Farber Cancer Institute. These two women have written extensively on pediatric palliative care. They note that “for children and

adolescents with life-threatening illness, developmentally appropriate advance care-planning documents can provide the opportunity to express their preferences for how they want to be treated should a time come where they cannot speak for themselves” (2014, p.836). *My Wishes* is a booklet designed for children under thirteen years of age. This document helps to facilitate discussions about end-of-life and guides parents and practitioners on how to begin the conversation while providing an outlet for children to be able to express themselves and their preferences for their care. *Voicing My Choices: A Planning Guide for Adolescents & Young Adults* helps young people to “communicate their preferences to friends, family and caregivers” (Aging with Dignity 2016). The guides acknowledge that when a person is living with a serious illness, there are many things that are completely out of control. These guides aim to empower the child and family by giving as much choice as possible to how young patients want to be “comforted, supported, treated, and remembered” (Aging with Dignity 2016).

Children frequently open up to the healthcare professional first (Davis & Holler 2015, p.8). Christine Harrison, PhD, is the Director of Bioethics at Toronto’s Hospital for Sick Children and Associate Professor of Pediatrics at the University of Toronto. Harrison noted that child life specialists in particular “may have expertise in gaining the child’s trust and cooperation” (2004). When using documents like *My Wishes* and *Voicing My Choices*, a CCLS may be the most appropriate professional to help guide a patient and family through the process and to get the most out of these meaningful resources. Doctors Patricia Baxter and Julienne Brackett from Texas Children’s Hospital found that “when families are given one of these tools, they often wish they had received it earlier in the disease course” (2015). One of

the goals of these documents is for a family to start a conversation that allows the family to work through and then review the goals of care. “Child life specialists can play a vital role in assisting clinicians and families with end-of-life discussions. Often, interactions with the child life specialist may reveal the child’s fears, concerns and wishes, as well as those of the siblings” ( Baxter & Brackett 2015). Drisdie Kee, a social worker in the pediatric intensive care unit at New York Presbyterian Hospital Weill Cornell Medical Center, stated how important it is for everyone to stay on the same page when making difficult decisions. Her advice to anyone working with families that are facing the immortality of their child is to “strive for a deeper understanding and a willingness to understand” (2016).

### **CREATING OPPORTUNITIES FOR CHILDREN: INDIVIDUALIZED CARE PLAN**

The Patient Self-Determination ACT (PSDA) does create opportunities for children to partake in decisions for treatment and “rights to determine the circumstances of their death” (Rollins 2005, p.261). Dr. Justin N. Baker is the Chief of the Quality of Life and Palliative Care Division at St. Jude Children’s Research hospital. He writes that “A practical approach for providing care for bereaved families begins when the child is first admitted for treatment” (2008). Baker has written in many journals and articles on end-of-life preferences for children and believes that bereavement care should be integrated into the mainstream of a child’s care. Baker has championed the use of Individualized Care Plans at the onset of a child’s illness so that “patient and family values, preferences, goals and needs” can be clearly identified to ensure that “appropriate goal-directed treatment options can be offered in times of uncertainty and emotional duress” (2008).

An Individualized Care Plan (ICP) is a tool designed to coordinate and integrate palliative care principles and practices into the ongoing care of children. Baker et al. writes that an ICP

Emphasizes the value of subjective experiences in the context of meaningful personal relationships and employs a patient- and family-centered approach in information delivery, needs assessment, and understanding of the patient's and family's illness experience. It aims to enhance communication about difficult issues by discerning patient and family values and priorities before critical decision points are reached (2008).

A child life specialist can be an advocate for the integration of an ICP and can help the patient, family, and medical team to navigate the process. The ICP model demonstrated in Figure 3. is designed to facilitate a combination of respect and support while meeting the goals of an individual patient, family, and medical team.

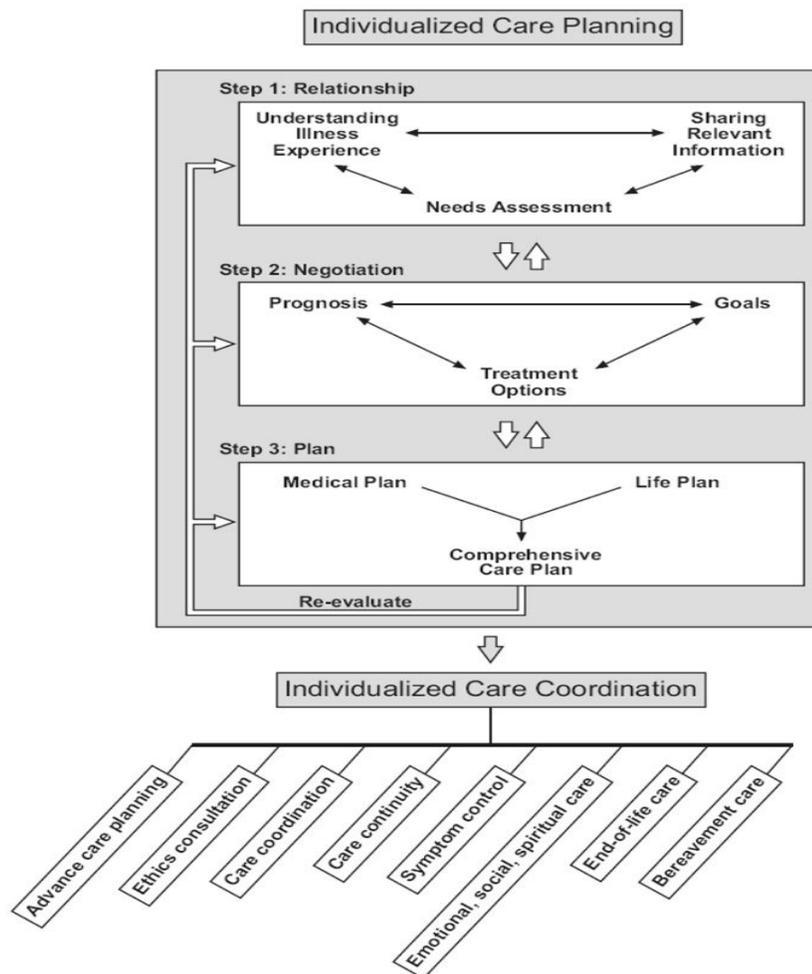


Figure 3. *The Individualized Care Planning Model. This model outlines a process to facilitate decision making and improve care coordination for hospitalized children with life-limiting or life-threatening illness (Ottolini & Ullrich 2014). The individualized care plan is implemented through individualized care coordination (Baker et al. 2008).*

An ICP can be essential to forming trusting relationships between the patient, family, and healthcare team by suggesting a format where information can be shared “non-judgmentally.” Open and clear communication can lead to optimal end-of-life decisions that “flow naturally from an ongoing conversation between the patient, family, and medical care team about care priorities” (Baker et al. 2008). “We need a plan to manage fear” Dr. Howell said in an interview in 2016. She went on to say that “information and a plan can help

to alleviate fear” for the patient, family, and medical teams. An ICP is a way to share information and devise a plan that helps to manage the unavoidable fear discussed by Dr. Howell.

Baker and colleague Pamela S. Hinds from the Children’s National Health System have studied end-of-life care preferences of children dying from cancer and their families. Their research findings showed that “children as young as 10 years recognized that they were involved in an end-of-life decision, understood its consequences, and demonstrated the capacity to weigh complex issues, including potential risks to themselves and others” (Baker et al. 2008). Including children in the discussion recognizes and respects the child’s “capacity for informed decision making” (Baker et al. 2008). A part of the end-of-life process is planning. A patient can have a voice in decisions based on priorities, values, and goals that can affect the desired location of death, care interventions, DNR status, withholding/withdrawing artificial life sustaining therapies, referral to hospice care, funeral arrangements, and how the child wants to be remembered. “Study findings indicate that many seriously ill children and adolescents can navigate a complex decision process in which risk is considered” (Baker et al. 2008). The context in which illness unfolds is personal. “Parents, surrogates and healthcare providers must recognize the subjective nature of suffering and respect the child’s autonomy and capacity to make decisions” (Baker et al. 2008).

For children to be able to make decisions they must be provided with accurate and specific information that is explained to them in a developmentally appropriate way. The inclusion of parents and caretakers is essential to the planning process of the imminently dying child. Research shows that “parents prefer to know at the time of diagnosis that their child may

not survive and want the treating team to alert them to changes in their child's clinical status and to available care options" (Baker et al. 2008). The recognition of a child and their parent's unique contributions to the discussion ensures a family centered care approach. There are few topics more sensitive than discussing the approaching death of a child with the child's parents. Prior to such conversations, the families religion, beliefs, customs, and values must be taken into consideration. The more prepared a family is for their child's end-of-life, the better their chances are of having a healthier grieving process. "Accurate information, delivered with skill and sympathy and updated regularly, lessens the parents' sense of helplessness and isolation and sets up a therapeutic alliance" (Black, 1998). Feedback from parents that were involved in the decision making process for their child's end-of-life was compared to feedback from parents who had not participated in decisions about their child's end-of-life. Parents involved in the decision-making process reported "less dissatisfaction with time spent with their child, fewer negative changes in family functioning, and more positive changes in feelings towards staff" (Thompson 2009, p.100).

## **ETHICS**

There are five recurring ethical questions in child life listed on p. 10 of the document, *Making Ethical Decisions in Child Life Practice* that are notably relevant to this topic.

What is a life worth living? Who decides the 'best interest' standard for a particular child? How do we define 'futility' in health care when a patient is 'beyond medical rescue? What are the parameters for involving children and youth in decision making about their own treatment and care? Under what circumstances should beneficence overrule autonomy?

These questions are not unique to child life and are fundamental questions in the study of healthcare ethics. The individuality of every person and every family is so uniquely and complexly different that it is impossible to have a blanket answer to any of the aforementioned questions that include personal variations of race, culture, religion, socioeconomic status, and other personal preferences. “Only the individual child and family can determine what is best for them, based on their particular values and life experiences” (Liben, 1996). One’s individual experiences, beliefs, culture, situation, personality and attitude (among others) make it impossible to make generalizations about how a family would or should answer any of these ethical questions. In an effort to acknowledge individual and familial differences, end-of-life decisions should be viewed through the lens of that particular family. Taking all these differences into account makes the establishment of laws and protocols difficult for hospital administrations and governing bodies to implement. Nevertheless, every child’s ability to have a say in their treatment and end-of-life decisions should be evaluated by a case-by-case basis” (Marker, 2013). A child life specialist can be an invaluable asset to advocate for the patient while navigating the emotional needs of the family and the medical process of the healthcare team.

The document, *Making Ethical Decisions in Child Life Practice* lists the “Principles of Professional Ethics. Among these principles are beneficence, nonmaleficence, respect for persons, and autonomy. Beneficence is the “duty to do good” where nonmaleficence is the “duty to avoid or at least minimize harm or burden” which includes both physical and psychological suffering. To prolong the process of dying is considered to be not in the best interest of the patient because it goes against both of these ethical principles. “Some of the

principal goals of health care are to maintain life and prevent pain and suffering, and not to unthinkingly prolong the dying process”(Harrison 2004). For instance, in the case of Julianna Snow, her medical team supported her parents decision to end Julianna’s life-prolonging treatment in order for her to live the rest of her life according to her personal preferences. Doctor Douglas S. Diekema is the Director of Education at the Treuman Katz Center for Pediatric Bioethics. In his paper entitled “Withdrawing and Withholding Life-Sustaining Treatment in Children,” he writes that the “burdens and harms of continuing a therapy frequently exceed any benefit or potential benefit the therapy might offer” that child (Diekema, 2000). Although physicians may make the argument that by continuing treatment the child’s suffering is being prolonged, the ultimate decision is legally up to the child’s parents or legal care takers. There must be a balance between the medical team and the wishes of the parents because it is the child’s family that will ultimately live with the decision for the rest of their lives. As a liaison between the patient, family, and medical team, a CCLS is equipped to navigate the middle ground by representing the voice of the child while respecting the parent’s role as the expert of their child. A CCLS can facilitate conversations that bridge the gap between the family and the medical team by reframing the focus to what is in the best interest of the child according to the child’s own preferences. The role of the CCLS is to promote a child’s ongoing participation in the conversation about treatment goals along with the parents and the medical team. When the role of the parents is respected, and a child’s voice is heard, there is a greater potential that the patient, family, and medical team will all be on the same page when goals of treatment shift to end-of-life care.

The term withdrawal of treatment includes two scenarios. The first is life support withdrawal (LSW) which includes extubating a patient and/or removing them from ventilator assistance, and withholding antibiotics and other life prolonging interventions. The second scenario is when the patient, the family, and the medical team conclude that intensive treatment may no longer be in the best interest of the child. The United Kingdom's Royal College of Paediatrics and Child Health presented a practice framework to identify five circumstances where withdrawal of life-prolonging treatment may be considered in children. Pediatric neurologist Anne Tournay, MBBS explains two of these scenarios; The 'no chance' circumstance for withdrawing treatment is applicable for a child where life sustaining treatment will merely delay death, without significantly relieving the suffering caused by the disease" (Tournay 2000). In this situation, "families must turn from hope for a cure to hope for a death without pain, and in a setting that is right for their unique wishes and needs" (Rollins 2005, p.255). The other scenario for withdrawal of treatment is known as 'unbearable.' "In the face of progressive disease, additional treatment may only cause further suffering, despite the possibility that it might have some potential benefit on the underlying condition" (Tournay 2000).

Medical ethics lead by the notion that when a life can be saved, it should be saved (Diekema, 2000). Ethically, the statement can be made that when a life cannot be saved, medical intervention should not interfere when death is unavoidable. When it comes to optimal ethical decision making, best practice requires "open and timely communication between members of the healthcare team and the child and family; respecting the values and beliefs of those involved; and the application of fundamental ethical principles, including respect for

human rights” (Larcher et al., 2015). Who determines best practice is not solely based on medical and clinical interest, but includes “other medical, social, emotional and welfare factors” (Larcher et al., 2015). If a child’s life could be saved by an intervention but the treatment would leave the child bedridden for the rest of his or her life, is this treatment worth pursuing for the child, family, or medical team? When included in the decision making process and given the option, some children can answer the question for themselves though legally a parent does not have to respect their decision. In unfortunate cases where there is discord between the medical team, the family, and the patient, an ethics consult may be utilized to minimize hostility and friction. An ethics committee can and should play a role in the palliative care process and can support the decisions and preferences that are documented in an ICP. Baker et al. points out that in times of extreme conflict, an ethical consult can assist in the resolution of complex situations and guide care policies that support the decision making process (2009).

## **ASSENT**

The concept of assent recognizes that children should have some authority over their own healthcare and “respects children as individuals with developing capacities for participation in health care decisionmaking” (Hilden et al. 2001). Assent is a non-legally binding term that “refers to a child's agreement with the proposed treatment” (Hildent et al. 2001). For children to assent to treatment, they must be “given both information that they can understand and some appropriate choice in their treatment” (Harrison 2004). Medical decision-making is defined by three hallmarks of informed choice: appropriate information, decision-making capacity, and voluntariness. Health care professionals and legal advocates

often struggle to determine the definition of “capacity.” Dr. Harrison writes that “capacity is not age-or disease-related, nor does it depend on the decision itself, but is a cognitive and emotional process of decision-making relative to the medical decision” ( 2004). Ethicists and palliative care professionals agree that when the age of assent is reached and the patient has the capacity to express preferences, choices should be offered and their wishes should be respected. Hilden et al. states that this is especially important in the area of end-of-life care, “when quality, not quantity, of life is the main focus. After all, who better can decide what constitutes quality of life for an individual than that person?” (2001). While addressing the role of adolescents in decisions concerning their cancer therapy, Leikin writes:

If a minor has experienced an illness for some time, understands it and the benefits and burdens of its treatment, has the ability to reason about it, has previously been involved in decision making about it, and has a comprehension of death that recognizes its personal significance and finality, then that person, irrespective of age, is competent to consent to forgoing life-sustaining treatment (1993).

Using an assent has a plethora of other benefits aside from demonstrating respect to the pediatric patient. Assents have been reported to lessen the child’s anxiety, improve cooperation with treatment, enhance the development of trusting relationships with adults, and improve long-term patient-physician relationships (Harrison 2004).

There are four basic elements of assent in pediatric practice that are listed in *End-of-Life Care: Special Issues in Pediatric Oncology (2001)*:

1. Demonstrating respect for the child as a patient and as a developing person by assisting the child to develop an appropriate awareness of illness.
2. Disclosing the nature of the proposed intervention and what the child is likely to experience (truth telling).
3. Assessing the child's understanding of information and the factors influencing his or her evaluation.
4. Demonstrating respect for emerging autonomy and the development of decisionmaking capacity by soliciting expressions of willingness on the part of the child to accept the intervention.

The four elements of assent directly correlate with three Child Life Competencies. The first is Competency 1.A. which is “the ability to assess and meaningfully interact with infants, children, youth and families” (Child Life Competencies 2010). When working with sensitive cases regarding end-of-life care, a CCLS must support the central role of the family. A CCLS is knowledgeable about the development of children and must be able to communicate and interact with children in accordance to their developmental level. Secondly, Competency 1.C. is “the ability to assist infants, children, youth and families in coping with potentially stressful events” (Child Life Competencies 2010). This competency mandates that a CCLS is proficient in providing and articulating coping strategies and addressing factors that lead to vulnerability and stress. The impending death of a child is a devastating and anxiety provoking situation for the family and at times the entire medical team. A CCLS is trained to provide strategies for effective coping across all developmental levels and can be an invaluable asset to the child’s family and the medical team. Lastly, competency 1.D. is “the ability to provide teaching, specific to the population served, including psychological preparation for potentially stressful experiences, with infants, children, youth and families” (Child Life Competencies 2010). This competency states that best practice for a CCLS is to accurately educate patients and their

families about procedures and expected outcomes. This competency echoes CCLS Belinda Sweett's recognition of the importance of voice, rights, inclusion, and knowledge when working with families. By educating children, they are included in their own care and are better equipped to make their own decisions. The process of assent gives the CCLS the opportunity to assess the individual patient's understanding of the treatment plan and the transition away from curative care. A CCLS can serve as a confidant who can clarify any misconceptions and reassure the patient that his or her pain will continue to be of primary importance to the medical team. A CCLS can also play an instrumental role in providing input (along with pediatricians, ethicists, legal counsel, and developmental psychologists) to create standards for decision making capacity in the pediatric population with respect to the individual's developmental level and personal desire and ability to participate in decisionmaking.

#### **CASE STUDY: LAURA VANDERBOS**

Research done by Meijer and colleagues examined the impact of chronic illness on peer interactions (2000). Study findings showed that the duration of illness was *positively* associated with social skills and assertiveness. The study suggests that a "possible benefit of the chronic illness experience is developing a greater facility for negotiation" (2000). Ernst, Johnson & Stark interpreted this positive association as the patient's "need to manage symptoms and interface with health care providers from a young age helps youth become more adept at identifying their needs and getting them met" (2011).

Laura VanDerBos was diagnosed with stage IV neuroblastoma in 2007 when she was 4 years old. Despite chemotherapy, radiation, and surgeries, Laura never heard the word 'cancer'

until she was 7 years old. Her mother, Trisha Cwayna, explained cancer by telling her that “there are yucky cells in your body that you have to get rid of.” Laura was in remission for three years before the cancer came back which prompted her parents to have what they called “the cancer conversation.” During this conversation Cwayna told her 7 year old daughter that “cancer is your own cells that got a little bit confused and made a mistake and made too many. And so that's why we take this special medicine.”

Laura journaled extensively in a diary after her eleventh birthday. She used the diary to express herself and process what she was going through. Her mother respected her wishes of privacy until eight months before Laura died. In hindsight she stated that she wished she had read it much earlier. Cwayna was struck by her daughter’s understanding of her illness and prognosis. Upon reflecting she noted that she did not think she gave Laura “enough credit for those things over the years” (Greco 2015). Being able to see her daughter’s own words opened up her eyes to realize that it would be ok to talk to Laura about the truth. It was through Laura’s journal that Cwayna discovered how angry her daughter was. “She was mad at me,” Cwayna confided in a phone interview. Cwayna has shared excerpts from Laura’s diary that shine a light on Laura’s experience, in her own words. The entries in Figure 4 and Figure 5 are a testament to Laura’s unanswered questions, her fear, her understanding, her anger and her frustration.

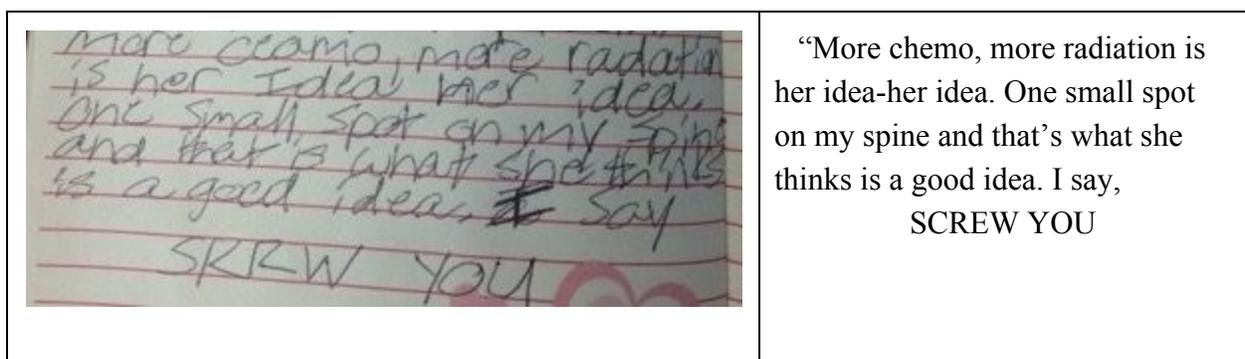


Figure 4. Excerpt from Laura VanDerBos’s Diary. With permission from her mother.

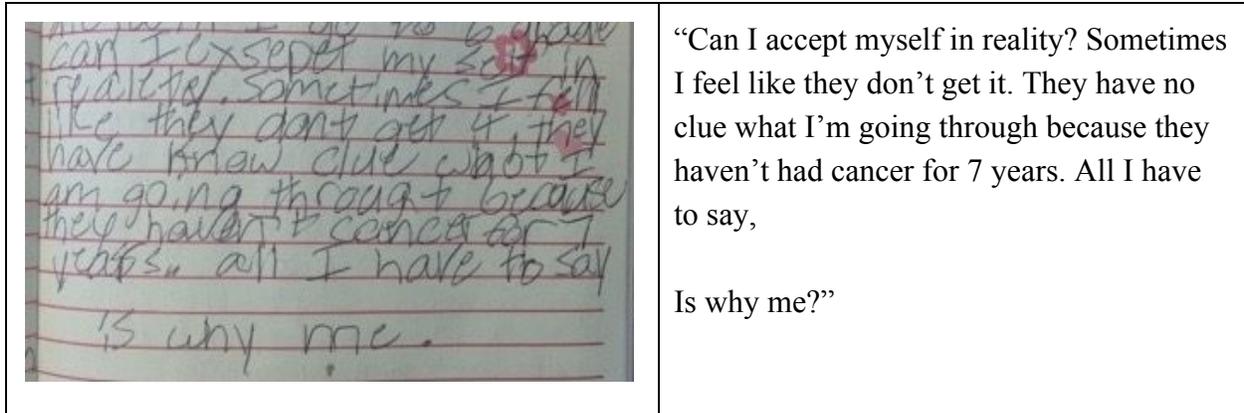


Figure 5. Excerpt from Laura VanDerBos's Diary. With permission from her mother.

As time went on, Laura was growing more frustrated. Her mother stated that she seemed to have difficulty interacting and would revert into her ipad or her artwork to escape. Cwayna believes that Laura may have struggled with expressing her own feelings because she, Cwayna, always grieved in private. “She couldn't be honest with me because I was hiding. I never showed my anger or frustration so she hid a lot of hers.” Figure 6 is an example of how children can have the capacity to understand the nature of their illness and mortality.

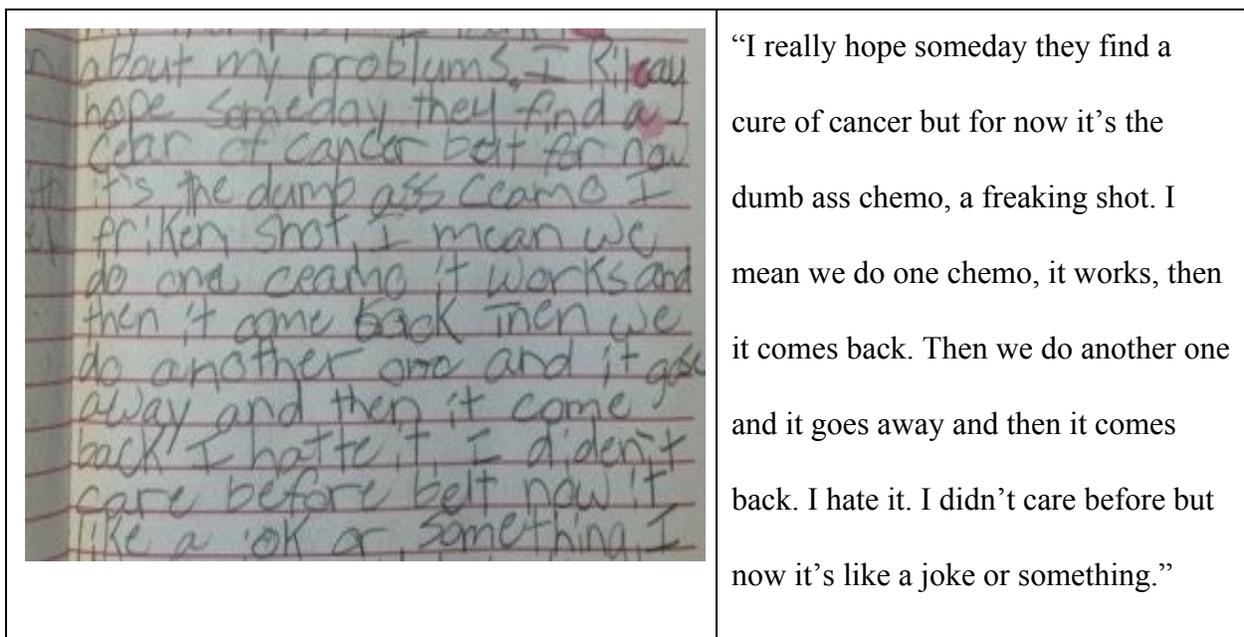


Figure 6. Excerpt from Laura VanDerBos's Diary. With permission from her mother.

Towards the end of June 2015, Laura was 12 years old, she was just over four-feet tall and weighed 63 pounds. She had a combined 4.5 years of intensive chemotherapies, over 20 surgeries, seven rounds of radiation, 2 bone marrow transplants, and a trial anti-body treatment. Since her diagnosis, Laura went in and out of remission 4 times. Treatment proceeded without asking Laura's permission. Dr. Howell noted that in many cases, part of the reluctance to have these conversations is the inability of the medical team and/or caregivers to recognize that a child has had enough. "As professionals, we need to be willing to go there" she stated. It was the following journal entry in Figure 7. That made Cwayna realize that her daughter had a voice that needed to be heard.

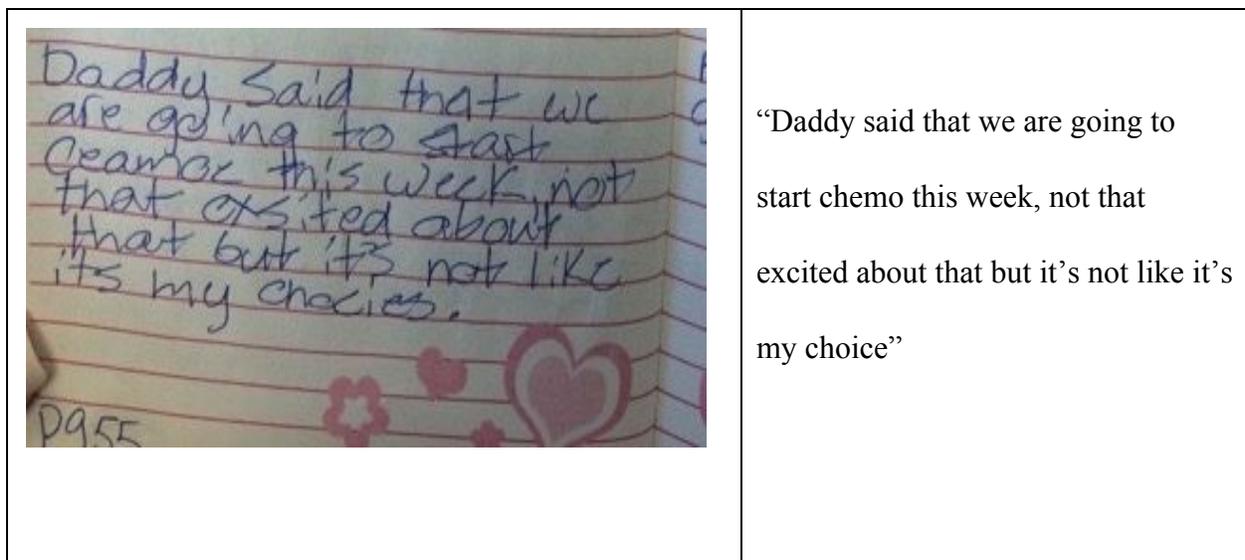


Figure 7. Excerpt from Laura VanDerBos's Diary. With permission from her mother.

Cwayna came to the realization that it was time to "equip her daughter with the language she needed to talk about it" (Greco 2015). She needed to start preparing Laura how to tell her own story. A turning point for the family was handing the reigns over to Laura. Laura sat down with her mother, doctor, and social worker and was presented with three options. The third option presented to Laura was that she could choose to do nothing except for treatment that

would help her to control her pain. She was told that the decision was hers and that her decision would be respected. Laura's response was "Really?! You guys will let me choose!?" Cwayna explained that Laura had a difficult time believing that the decision was up to her. She was convinced that her mother or doctor would go behind her back. Once Laura was convinced that this was really her choice to make, Cwayna said that she looked instantly relieved, as if a huge weight had been lifted from her shoulders. During the conversation, Cwayna told Laura that she had the power to make decisions for herself. Cwayna said it was as if the "shackles came off and the wonder woman cape came on" as she processed her new gift, the gift of having a voice. There was absolutely no hesitation from Laura when she told her parents and doctors that she wanted to stop "immediately" and she understood that this meant she was going to die. At that point, Laura stopped curative treatment and moved to at-home hospice care. The goals of the family changed significantly from diagnosis in 2007 to her relapse in 2015 where she began to discuss how she wanted to live before she died. Laura helped to design her own plan of care including how her pain would be managed as her symptoms progressed. Cwayna made the observation that letting Laura know her fate and helping her to understand what was coming next empowered her to ask for what she truly wanted and needed. Laura's ability to ask for what she needed is poignantly demonstrated by Laura in Figure 8.

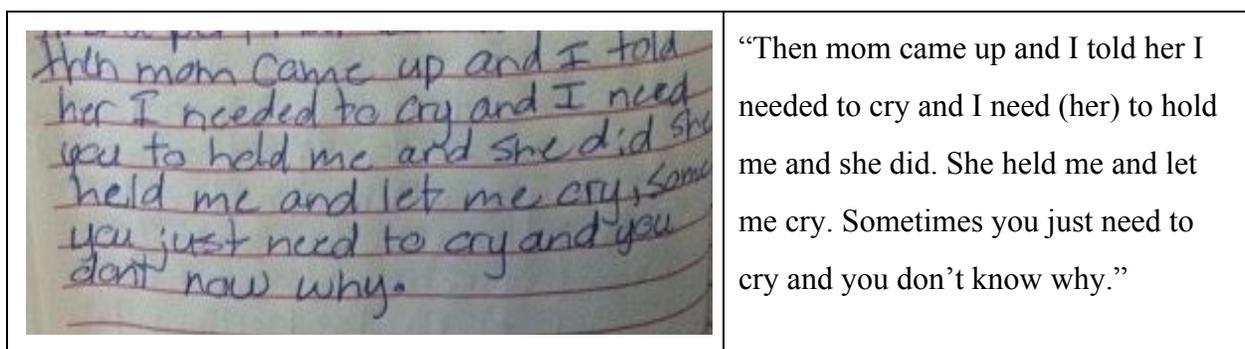


Figure 8. Excerpt from Laura VanDerBos's Diary. With permission from her mother.

Genevieve Lowry M.Ed, CEIM, CCLS, advises her child life students that "children ask what they need to know, but they also need to know the door is open to ask," a sentiment that proved to be especially true for Laura and her family. Once that door was opened, Laura walked right through it and let everyone know what she needed and wanted. "She wants to know what's happening and wants to be part of the decisions," Cwayna explained. Cwayna stated that once Laura recognized that dying was ok to talk about, she talked very candidly about her "transition." "She, almost everyday, has something to say about it."

"She's really leading the way," said Cwayna. "She's happy. She's playful. She's talking about making sure her favorite things are given to her friends and family. I feel like this time with her is a real gift." (Greco 2015).

Laura helped her own mother to truly come to terms with the inevitability of her death. For Cwayna, "the thought of her suffering was so much worse than the thought of her passing" (Greco 2015). Simon Newell, a neonatal consultant at Britain's Leeds General Infirmary has written that "for some, continuing life-sustaining treatment is simply prolonging suffering in the face of the inevitable" (2016). For Laura and her family, this was certainly the case. Laura knew that she was done with treatment and was "going to be an angel" (Greco 2015) and she found a way to cope through talking to those around her and using her own sense of charm and sarcasm to face her own mortality. "Sometimes doing *everything* you can means stopping before you come to a tragic end and allowing your child the time to process. It's the gift of letting them say goodbye," Cwayna shared. One of Laura's biggest concerns was about her family and friends. She dedicated a lot of time to leaving memories for her family in the form of recording messages for them to listen to and decorating and filling memory boxes and leaving a note for her brother

that said, “You’ve always been there to watch out for me and soon I’ll be watching out for you from high above.” Laura has always been a perfectionist and worked on everything so it was just the way she wanted it to be. For Laura, planning for her death was a way to take control of her life. Anticipating her death, Laura has wrapped and picked out birthday presents for her mother to give to her two brothers this upcoming year. “I just have a lot of things I want to tell people” she told Rachel Greco, a local reporter for the Lansing State Journal in mid September, 2015.

## **CONCLUSION**

There can be differing opinions about what the “duty to do good” is in pediatric withdrawal of care scenarios. “The capacity of modern medicine to prolong life is now so advanced that there is concern that the prolongation of life becomes the sole end, irrespective of the harms it may impose” (Harrison 2004). Where some would argue that “doing good” is keeping the child alive no matter what the physical or psychological toll is, others would say that “doing good” by ending the suffering is the most loving decision to make. “If possible and indicated, caregivers should invite children to participate in decisions about their own care and honor their wishes” (Baker et al. 2008). By including children in the discussion, caregivers and healthcare professionals are able to decipher what “doing good” means for that individual child. The principle of respect for persons recognizes that all patients have the right to receive treatment with dignity. All patients, regardless of their age, deserve to be acknowledged, respected, and valued. When a child is stripped of the right to make decisions, this ethical principle is not being met. The principle of autonomy is the “duty to respect and foster self-determination and freedom of action of the individual” (2000). Health care staff and

families should always be encouraged to respect a patient's decision-making capacity and recognize that any individual has the right to make decisions about their own body.

“For lack of a better term, it's choreography and we have a say in the matter” Dr. Howell shared in her personal interview. “Let us as professionals, allow the child to write the script, the score, to choreograph the last dance” (Howell 2016). A CCLS has the ability to help families to configure a semblance of order and meaning. If this task can be accomplished, then “the memory of the last dance is going to last forever” (Howell 2016).

Dr. Howell shared her belief that working with children and families at a child's end-of-life is a privilege. In this culture the idea of children dying is often taboo to discuss. From the moment a human is born much time is dedicated to every step of life. The choices that a person makes about his life is what makes each individual unique. People are given the opportunity to plan for their lives, it should be said that people, even children, should also be given the opportunity to plan for their deaths. If conversations about choices for treatment and death occur earlier, then there will be more opportunities and more time to make decisions in order for children to choose how they want to live before they die. A CCLS can aid in navigating these conversations and can help families to cherish the legacy of a child's life in a greater context than their life with an illness. The role of a CCLS can empower a child by giving them the power of a voice.

On November 2nd, 2015 Laura VanDerBos took her last breath. In the end, Laura had control and choice. Her mother relinquished the power over years of watching her daughter battle this illness. “Your child can probably handle more information than you think they can” Cwayna said. For Cwayna, giving Laura the ability to participate in medical decisions

empowered her. Laura's participation gave her the courage to tell her mother that she was ready to die and did not want to do any more treatment. "Honoring their decisions are very crucial" Cwayna advised. Honoring Laura's choice gave Laura the freedom be in charge of her own body. She was finally given the information to understand and question the ramifications of her decisions and therefore was given the gift to live according to her terms while dying. The freedom to make decisions allowed her the opportunity to "process it and make peace with it." "I have zero guilt" says Cwayna. "I honored her, I know I followed her wishes. I have no regrets at all" (2016). Cwayna disclosed that the greatest part of telling Laura the truth and letting her decide was the freedom it gave her. "I feel very proud of myself for telling her. It was the best gift I could have given her" said Cwayna.

Cwayna acknowledged that "everyone has to do what they find right in their own heart and live with themselves." The only thing Cwayna would have done differently was that she wished she had given her daughter that power sooner had she known how much that would have set her free. When asked what advice she had for other mothers of dying children she laughed and said, "Let them live a little, they deserve that dignity."

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**PERMISSIONS**

I, Trisha Conway, give permission to share the story  
print parent's name

entries of my child, Laura VanDerBos.  
print child's name

I understand that the purpose of the information is to assist a graduate student in meeting the requirements of a course that involves presenting information and research

I understand that the info. will be used solely for educational purposes at the Bank Street College of Education.

Undersigned:

Trisha Conway 4/18/16  
Parent's signature Date

[Signature] 4/18/16  
Student Signature Date