



Child Life at End of Life: Providing Child Life Services in a Pediatric Home Hospice Setting

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When asked about the role of a child life specialist, people in our field generally think of helping children cope with hospitalization, invasive or painful procedures, and new diagnoses. When I began working in a hospice setting, I had to rethink my role and how I could use my skills as a child life specialist to support patients who are dying at home. The children I work with are not occasional visitors to the hospital, terrified of medical staff, and anxious about getting pokes; they are the experts when it comes to healthcare. Most of them have seen it all, developed close friendships with their medical staff, can tell you more about their diagnosis than most medical students, and are most often exhausted by it all. The patients I work with are now at the place where there is no more treatment available, so they are no longer going to the hospital for chemotherapy and scans, but instead have been given the opportunity to die at home surrounded by their family and friends.

Just like any other child life position, I am frequently educating staff about my role on the interdisciplinary

team, including when to make a referral for child life services, and how to introduce my role to the family. Once I am in the home, I find I have to re-introduce child life services as many of the patients know child life as the person who taught them how to cope with getting their port accessed, or the person who organized BINGO on the floor each week. I typically tell families that the major differences between hospital child life specialists and hospice child life specialists are that I am able to work with the child in their space at a time during the day that is convenient for them, and I am able to work with the child on their individual needs, rather than base services around the medical needs (i.e. procedures, exams, physical therapy, etc.). However, before I was able to explain my role to families and staff, I first had to really understand how I could utilize my child life skills when there are no hospitals, painful procedures, or new diagnoses. I quickly realized that the normalization and preparation skills I had learned throughout my education and prior child life experience were the same skills I needed now. I just had to look at them through a different lens.

Normalization

Normalization is a core child life concept. In the typical hospital setting, normalization means normalizing the environment by creating a structure and familiarity in an unfamiliar and often scary place. However, when a child is at home, as they often are in hospice, they are in their natural and normal setting, so what do we need to normalize? Working in hospice, I normalize their feelings. I let the patient, siblings, and families know that they are not alone, and that what they are experiencing and feeling is normal and okay. The fear of dying is normal, the loss of control is normal, and the hope for a miracle even when they know it's not possible is normal. A large part of my role is normalizing the abnormal, which in this case is the death of a child.

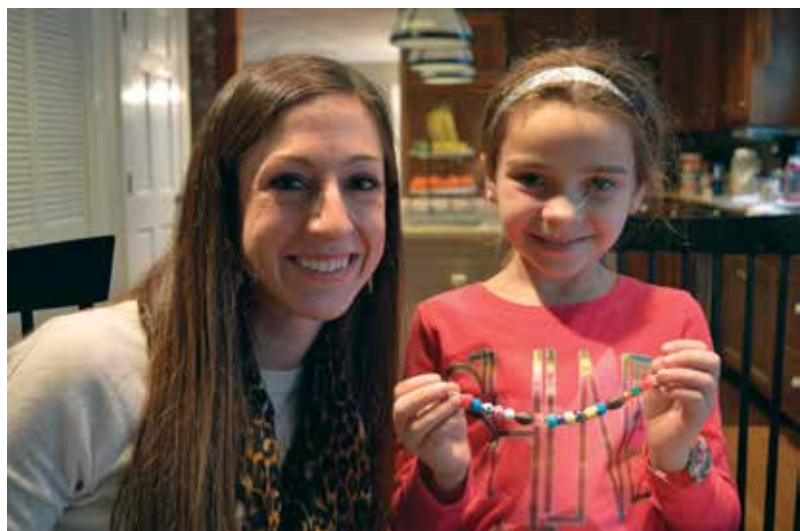
When a child is dying, they may not know how to live their last few months. However, most children that I work with at this phase really desire to be “normal.” This usually means going to school, being around their friends, going to the movies, planning for the future and other typical activities that they may have been able to do before they were sick. As a child life specialist, I have the opportunity to use my creative skills to figure out how this can be done; whether it is skyping with the school, bringing the movies to the child, allowing the child to dream about who they will be when they grow up, or encouraging the family that it is okay and safe for the child to still do “normal” things. Modeling that the child can still participate in normal activities is a great way to encourage the child's caregivers to allow them to do this, even when it may feel scary. One way I model for parents is through play.

Play

As every child life specialist knows, play is a universal language. Play is the core of what we do, whether it is in the hospital, school, shelter, or in the home. Play is the most important aspect of our jobs, and play is just as important at the end of life, even when play may seem impossible. While some may view play as the physical act of playing a game, throwing a ball, running, jumping, and laughing, when a child is dying we have to think of play in broader terms, as activities that bring the child joy. With one patient, watching her favorite cooking show while getting her

feet rubbed brought her joy. For other children, going outside to ride bikes might make them feel joyful; being read to, listening to music, or even watching others play can bring joy. Play in the home setting can take different forms based on who is home at the time or the child's energy level. I meet the child where they are, whether it is the act of simply being with a resting child, or the act of engaging in physical play.

Play in the home setting also allows the opportunity to engage siblings, family members, and friends. In some situations, I work with the siblings and provide them with a safe space to ask questions, discuss their feelings, process information, and interact with their sick brother or sister. Other times, I may focus my visit on the patient only, which can also allow the opportunity for the parents to engage, or can allow parents to have that time to themselves, which they rarely have at this stage of their child's care.



When a child is dying in the home, the family can feel overwhelmed and they often view my role as helping the child to delve deep into their child's feelings about death and dying. However, as we know, a trusting relationship must be built before this is feasible, and often this rapport is built through play. When a child is in hospice care, I sometimes have months to develop a trusting relationship, and other times I have days or weeks. Sometimes, a child or adolescent may decline child life services, and validating their feelings about this decision can be the first step in rapport building. In other situations, I may be working months with a patient and we may not ever reach the point of talking about deep feelings before a child dies.

Meeting the children where they are is a practice all child life specialists know, but at the end of life this can take many different forms. When I am providing services, I always strive to provide them with joy and happiness at the end of life, which I view as the best and most important service to provide.

Preparation

In a traditional child life setting, preparation generally means preparing a child for a medical event (IV start, surgery, hospitalization, discharge, etc.). We use child friendly terminology, medical play, and role reversal to teach the child about what is going to happen to them and offer them some control and mastery over their experiences. In the hospice setting, however, preparation looks a little different, as I am preparing patients and families for what to expect at the end of life and after the death.

Siblings

An important part of my role in hospice is working with the siblings of pediatric patients and preparing them for the next few months and years. Questions that generally come up include: Can my brother or sister still play with me? Will I still be a brother or sister after my sibling dies? What will our family do after he/she dies? How will I know when my sibling is actually dying, what will he/she look like? What if I am the one who is with him/her when he/she dies? What is a funeral? Where will his/her body go? The preparation skills I've learned as child life specialist help me work through these questions with the siblings. Educating the siblings about what death may look like, providing opportunities to be involved in the decision making for services, and possibly even touring the funeral home are all opportunities to prepare a sibling. When I am able to openly prepare siblings for a death, I am able to discuss their choices, such as whether they want to be in the home when their sibling dies or when their body is removed, or whether they want to attend the funeral or have a special role in the funeral. Often, I find that the children already have the answers; they just need someone they can trust to openly talk about what they think will happen, and that is where child life can help.

Legacy Projects

In some cases, when working with pediatric patients at the end of life, preparation can take the form of legacy projects. Creating photo slideshows, making blankets out of their favorite t-shirts, writing letters to their loved ones, and taking special trips can all be ways that we help children prepare to die. Some children may be able to discuss their own legacy and how they want to be remembered. For example, one teenager I worked with was able to tell her parents that after she dies, she needed to know that they would get out of bed. After this teenager died, her parents let me know that on the days when they thought it would be impossible to get out of bed, they heard their daughter's voice telling them they had to face the day. This patient was preparing her own family for life after her death. Providing opportunities to speak openly and honestly about the choices patients and siblings have at the end of life helps to empower the children and provides them with choices at a time when there are not many choices left. However, the opportunity to utilize preparation skills does not always exist in the hospice setting. A family must be open and honest about the dying process before a child life specialist can speak openly with the patient or siblings. When the words "dying," "hospice," and "end of life" are not openly discussed in the home, it is important to respect the family's wishes and utilize other important child life skills in order to have a positive impact at end of life.

People often ask me "How do you do your job?" or "Why would you want to do that?" While people always have questioned how I could work with sick kids, when I now tell them that I work with dying

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Child life specialists are experts in child development, who 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.

kids, their reaction is even stronger and most often a conversation stopper. However, if I can be that person who puts a smile on a child's face, whether they are in the hospital undergoing a procedure or dying at home, that is all that matters. Being a child life

specialist in the hospice setting allows me to help make this unimaginable time just a bit more joyful and make the end a little bit easier. That, I tell people, is why I chose child life and why I love this work.

The Child Life Council (CLC) represents the child life professional community. It provides members with professional development programs and resources, facilitates the exchange of knowledge and best practices, and distributes information about the needs of children experiencing stress and trauma. Members include child life specialists, child life assistants, university educators and students, hospital administrators and staff, school teachers, therapeutic recreation specialists, and others in related fields. More information is available at www.childlife.org.

Care Dimensions is the largest hospice provider to adults and children with advanced illness in Massachusetts. As a non-profit, community-based leader in advanced illness care, Care Dimensions provides comprehensive hospice, palliative care, grief support and teaching programs in more than 90 communities in Eastern Massachusetts. Founded in 1978 as Hospice of the North Shore, Care Dimensions cares for patients – in their homes, in long-term care and assisted living communities, in hospitals and at our Kaplan Family Hospice House – throughout all stages of advanced illness. Learn more at www.CareDimensions.org.

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