Child Life from Another Perspective

"The Play Lady". "The Toy Lady". "The Playroom Worker".

As Child Life Specialists, we get called many names that might seem to minimize our education, insight and professional training. People tell us how 'nice' it must be to play for a living (and yes, it is!) and wonder aloud about the validity of play as a treatment modality. What they fail to recognize is the *importance* of developmentally appropriate interventions when working with children. It is through that expertise – the ability to understand how development affects a child's perception of his or her world – that a Child Life Specialist is uniquely trained to assist pediatric patients through their illness / hospital journey. And it is this same expertise that can be tapped to benefit other patients in the health care system.

I work at the University of Texas MD Anderson Cancer Center in Houston, Texas, USA. I am a trained Child Life Specialist, and in my career at different hospitals have worked with children with cancer, with kidney and liver transplants, with orthopedic birth defects, and with premature infants in the neonatal intensive care unit. Although I love working with pediatric patients, I now find myself happily being of service with adult cancer patients at M.D. Anderson, utilizing my training in child development to help children whose parents (or grandparents) have cancer. My program at MD Anderson is called the **KNIT** Program (Kids Need Information Too). The KNIT Program helps patients in all phases of cancer treatment: those adults who are newly diagnosed with cancer, patients who are in active treatment for their cancer, and patients whose treatment has not been successful and who are now looking at end of life/palliative care issues. (Although my center deals strictly with cancer patients, most of this information can be adapted for any disease process that adult patients are encountering.) I like to call these adult patients with children *parent patients,* as it describes the combination of roles and responsibilities that is presenting the conflict.

So, how does one navigate the difficulty of being a parent of children and now a patient with cancer?

Patients who are newly diagnosed have lots of questions and concerns: Should I tell my children about my cancer? How much should I tell them? What information do I give them? Is there a right way to present the information? And lastly, do they really need to know?

The natural course of action for most parents is to keep things quiet and not 'upset' or 'worry' the kids. They may use terms like mom is "sick" or has a 'boo-boo', but rarely do parents feel the courage to talk openly with their children about the name of the disease, what the treatment is called, and how it will change things in the family. Parents mistakenly feel if they just pretend everything is "okay" then the kids will not be any the wiser to the changes that are taking place.

The reality (as we all know) is that children are perceptive enough to understand when something changes in the family dynamic, especially when it is something as scary and routine changing as a cancer diagnosis. They see that mom is going to the doctor a lot more than usual. They see that daddy doesn't play or do all of his normal activities. They see the parent gaining or losing weight (and hair) and maybe there are other outward signs of disease as well (i.e. surgical scars). If we just use the word "sick" then we are leaving the children open for many opportunities for misunderstanding. As an example, imagine a child whose parent has been in treatment for some time, and knows that daddy is "sick" but that is all that has been shared with the child. Then comes a day when the parents are at the hospital and the child is staying with grandparents, and the child wakes up with a sore throat and fever. The grandmother says to the child "You are sick, we need to go to the doctor". Given what the child knows about his parent being "sick" and seeing the parent's many absences and bodily changes, imagine what that child might now think ('oh, my, what happened to my dad with his sickness will now happen to me'…) What a breeding ground for misconception and misplaced fear…you can imagine what conclusions that child might draw about what is going to happen to *them!* They don't know that their "sick" is different from their parent's "sick"!

Being egocentric, children also tend to assume that any change is probably a result of their own actions. So it is natural for a child to assume they must have done something bad if a parent suddenly is gone from home more frequently, isn't picking them up at school or playing with them as often, or is in bed not wanting to be disturbed. This is not limited to young children; even elementary aged children up to 10 or 11 will take responsibility for the parent's change in involvement, and assume that it must be something "they" (the child) did that is resulting in the parent's change in behavior. It is important, therefore, for children to have honest information about why this change has occurred.

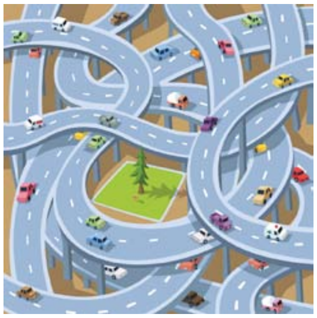
Beginning the conversation is often the biggest stumbling block for parents who know they should talk with their children but have no idea where to start. I like to suggest to parents to remember the three "C"s of talking to their children about their cancer diagnosis: the illness is called cancer, it is not catchy, and it is not caused by anything the child did or did not do. By using this method, we allow children (even those as young as 3 years old) to give a name to the parent's illness, thereby reducing the possibility of confusion about the parent's illness and any other illness the child might get during the parent's treatment. We help children understand that unlike the illnesses they are confronted with in school which require covering your mouth or staying home from school (flu, sore throat, etc), cancer is not catchy (contagious) and children do not have to worry about catching the illness from their parent. And we reassure children that nothing they did caused the parent's cancer. The parent didn't get cancer because the child misbehaved or because the parent asked the child 1,000 times to pick up their toys!

Describing what cancer is can also be a daunting task. First of all, we need to remember that the word "cancer" doesn't carry with it the negative history that most adults automatically associate with the term. To them, it is just another word. Children younger than 5 years old will generally accept the name of the disease as an adequate amount of information. In fact, most parents report back to me that when they told their 4 or 5 year old children the name of their sickness, their kids said "okay" and ran off to play. Older children, however, can understand basic scientific information and the level can be adjusted to their age. For example, children know their bodies are made of up millions of cells, cells that are always growing more new cells. A good way to demonstrate this is reminding children how their skin "grows new skin" when they skin their knee or elbow, or have a cut. In this same way, inside the body of someone that has cancer, there is a "misbehaving" cell that doesn't behave right. (I like to ask school age kids if they have ever had any students in their class that misbehave…the answer is always yes!) Cancer cells are like these cells, only they grow and make new cells even faster than our healthy normal cells. The cells generally like to stay together, in a "glob" of cells, and sometimes this glob is found in a leg or in someone's tummy, or in their head, and they are called a tumor. These cells will take the place of the healthy cells and so the doctors need to do something to try to make them go away.

Using visual images for children is a technique I always find helpful, particularly when explaining new or difficult concepts. An image I like to use to demonstrate this "glob" of tumor cells is a bunch of grapes. Children usually know what grapes look like, all bunched together. But they also know that sometimes some of the grapes fall off the bunch (much like cancer cells that roam throughout the body).

So this visual not only helps to explain a tumor but will also assist when explaining why and how chemotherapy works. For children over 6 or 7 years of age, this explanation can occur in one setting but please adjust for their ages (that is, lengthier explanations/more details for older children.)

When a patient has leukemia, we adjust this explanation just a bit. Leukemia is a special kind of cancer where the cells don't stay together; instead these cells float around in the bloodstream. Another image I tend to use during an explanation of leukemia is that of a freeway system. The freeways represent the human bloodstream, which traverses the body from the top of the head to the bottom of the toes. Leukemia cells live here, in the bloodstream.



Utilizing these two images will help in an explanation of how chemotherapy works. I mentioned before that the tumor cells sometimes fall away from the tumor (bunch of grapes) and if that happens, they too float around the bloodstream (freeway system in our body). Like the leukemia cells, the doctors want to try to get rid of those cells. Explain that there is a special medicine, called chemotherapy, which is used to try to find and attack these cancer cells.

Chemotherapy (chemo) works kind of like a video game (again, using an image that the majority of children can identify with). The conversation might go something like this: "Remember we talked about how cancer cells grow really fast, faster than normal cells? Well, the way the chemo medicine works is like a video game. You know how video games are played? Okay, well, the chemo is kind of the search and destroy tool. It goes through the body in that freeway system, looking for fast growing cells in the bloodstream. If it sees fast growing cells it zaps them, just like in your video games." This explanation also works for those times when the parent's hair will fall out as a result of the chemo. The chemo looks for and zaps fast growing cells, but it doesn't always know the difference between good fast growing cells and bad fast growing cells. The cancer cells are the fast growing cells we don't want, but hair, that is a good fast growing cell. (Remind the kids how often they have to get their hair cut!) When the chemo is going on its search and destroy mission in the bloodstream, it will zap fast growing cells, and many times those cells are hair cells. So…sometimes a person's hair falls out from the chemo. But once the medicine is finished the hair will grow back. (An added benefit to this conversation is dispelling the frequent misconception that it is the cancer that makes someone's hair fall out.) Chemotherapy also will be used to try to kill some of the tumor cells, either as a main treatment or to try to shrink the tumor before surgery, so children will have an understanding of why each treatment is used to treat their parent's cancer.

For a patient that is going to have radiation, it can be described as a special light that goes through the skin without hurting the skin. It is aimed at the tumor, and it tries to kill the tumor cells to make the tumor smaller, usually in preparation for surgery.

Other topics that may come up after a new diagnosis refer to how the family's routine will stay the same and what will change. Again, many times these issues will escalate in importance based on the child's age. Teens will be most concerned about how this affects their world, since, as we all know, for teenagers it is "all about them". It is important that parents remember this developmentally normal perspective of teens, so they aren't disappointed or angry with their teens if they seem a bit self-centered. Some topics that should be discussed with all children may include some of the following:

> How often does the parent expect to go to the clinic or hospital?
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> Who will pick up the kids from school if the parent's appointment runs late and they can't pick up the child from school? (If possible, identify 2-3 friends/family members who will be the pick-up person, and share this with the children. That way the child knows that they are not going to be stranded at school if the parent is admitted to the hospital unexpectedly). If some chores need to be reassigned in the family, try to make it a joint decision by the family. Decide what is essential and what can be let go of for a short time.
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> Reassure children that whenever possible, their routine won't change any more than necessary. School is still priority number one for children. Help them understand that their focus needs to be on school, that this information about the cancer has been shared with them so that there aren't any secrets in the family, and that if anything changes, they will be told. In this way, the children are reminded that they can concentrate on school instead of worrying about what their parent's *aren't* telling them.
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> Here in the United States, we encourage parents to disclose information to the children's schools. Children spend a great deal of their day at school, away from their parents. Generally, the teachers will be the first to spot any changes in behavior, so they are an important component in

observing how the kids are doing with the changes in routine at home. Also, this allows the teachers to have insight to a child's change in attention/distraction or work ability. There will be differences in cultural aspects of sharing this information with teachers, but given the time that teachers spend with children, we feel it is most important for them to be informed about what is going on with the student.

To assist with the issues children face when a parent is being treated for cancer, support groups can be a great resource. At M.D. Anderson, we use a program design formatted by the Children's Treehouse Foundation (childrenstreehousefdn.org). They have a 6-week program that focuses on the myriad emotions children face after a parent's cancer diagnosis and how to manage them: happy, confused, sad, angry, and scared. There are weekly hands-on activities that correlate with the 'emotion of the week.' Peter VanDerNoot, Children's Treehouse founder, has put together an amazing training program to initiate such a support group. I encourage you to visit the foundation website and read more about how to implement such a support program for children of adult patients in your own hospital.

When Things Get Bad

What happens, though, when things get bad? Unfortunately, with a diagnosis of cancer often comes the realization that the best medicine isn't working and the patient is going to die. These are tough issues and again, children have a right to know what is going on in the family. The reality is, if a parent is going to die, the children can NOT be protected from that fact. Eventually, they will find out, and in most cases, children find out immediately prior to the parent's death or worse, after the death has occurred. Telling the children ahead of time, in an appropriate time and manner, allows the child to be a part of the family experience and also increases trust in the child's caregiver.

When a parent has been told that there is no more treatment for their disease, they begin to prepare for what will happen next. Often, they feel that their children should not know anything, because it will be too disruptive, or too scary, or that they won't be able to continue with their day-to-day lives. But the reality is that children, just like other family members, need honest information in order to prepare for what the future holds. When children find out (later) that the surviving parent or other family members knew to expect the patient's death and chose not to share it with the children, there is anger, resentment, and a deep sense of isolation and loss. And, perhaps most importantly, they lose forever the opportunity to say what they needed to say to that parent one last time.

How to approach this information sharing is of course a delicate issue. Children need to hear honest information, just like they do when a parent is diagnosed, but it is equally important that this news is delivered in a developmentally appropriate way. This is one of the reasons that Child Life Specialists are best equipped for this kind of assistance to parent patients, because treating children in a developmentally appropriate perspective is *what we do.* Both the content of the information and the timing is age dependent.

Teens (12 and older)

Teens, by their very nature, want to be included. They are the most likely to be highly insulted and resentful of secretive information. And while they can be more dramatic than younger children, they are still developmentally and emotionally able to handle more information than their younger counterparts. One of the best ways to approach them is to start by gauging what they know about their parent's illness. ("You know your dad has been battling this cancer for 8 months now. I know things have been kind of hectic, but I was wondering if you would tell me what you understand about his treatment and what the doctors have been doing to treat his cancer.") This allows for an assessment of their perception and an opportunity to correct any misinformation prior to giving them a difficult update. Giving this information is never easy, and it can be very uncomfortable for the family or staff member delivering the news. Keep to facts, and be direct. ("The doctors gave us some difficult news yesterday. The medicines your dad has been getting aren't working; the cancer is continuing to grow into different parts of his body. At this point they feel that giving his chemo might make him worse and they are going to stop his medicines. His cancer is not going to be cured. Do you know what that means?") This conversation will most likely involve tears and possibly some outbursts of anger. Validating their feelings is the best approach. It does stink. It isn't fair. And everyone wishes it wasn't this way. At this point, they need to be reassured that they will be cared for, and that they have options about how much information they want from here on out. ("As dad gets weaker, if the doctors have an idea about how much longer he will live, do you want that information?") Teens will differ on how much information they want, based on their personality, their family style of communication, and their perceived ability to handle these circumstances. Obviously, culture plays a big part in this as well. In many cultures, children accept that adults will tell them what they need to know when they need to know it. However, as teens are developing into young adults, overall their wishes (across cultures) are to be treated in a more adult manner. This includes having an open system of communication and not keeping important information from them. Ideally, this information should be provided to teenagers weeks (4-5) ahead of the patient's death. This of course is not always possible, but the safe rule of thumb is that whenever the adults know about a patient's terminal status, teens should know earlier than younger children.

One thing to remember: as mentioned in the topic of diagnosis disclosing, teens at this age can be pretty self absorbed, and their peer group is usually their most important concern. So even with difficult information like this, teens may revert to reliance upon their social group for support. They may feel an immediate need to distance themselves from the truth at hand and escape to a safe place with their friends where clothes/activities are their greatest concern. This is a developmentally appropriate response and allows them time to process the information they have received. Allow them time to be with their friends, but revisit the conversation within the next day or so. Encourage them to talk with a friend, a teacher/coach or an adult relative about what they have heard.

Children 7-12 years of age

Like teens, it is important to assess what school aged children comprehend about their parent's illness. Ideally, they would have been given honest information about their parent's diagnosis, but many times the family has only used the word "sick," then when the news is delivered that the patient won't be cured, families realize they need to start giving the kids more honest information. So for children of this age, the first step must be to assess their understanding. ("What can you tell me about why mommy goes to the hospital so much"?) Here you will encounter kids at any point along a continuum of not knowing anything (therefore requiring a crash course in explaining cancer) to being relatively well informed about their parent's disease. I like to proceed then with a question for them: "Have you ever thought about what would happen if the medicine didn't work?" This lets you know how much they have thought about the possibilities and also is a good way to open the conversation about the future. Again – "The doctors have said that the medicine isn't working, mommy's cancer is very strong and it is continuing to grow in her body. They are going to stop giving her the medicine because it is hurting her more than helping her. But if the cancer keeps growing, what do you think will happen?" Answers might be anything from a shrug of the shoulders to answers like "we could try different doctors/medicine" to "she could die". Generally I like to let kids go through their choices about what might happen next, because in this age range (even at the younger end) children are becoming aware that sickness can result in death. Allowing them the time to give voice to what could happen is usually the first time that they have actually said "she could die", even though they might have thought about it. Kids (and actually many adults) carry the mistaken notion that 'saying it might make it happen' and so they have never talked about their concern that this disease could make their parent die. Being able to verbalize their fears / concerns is an important first step to coming to terms with the future reality.

Sometimes, kids honestly have not thought about it the fact that their parent could die. The parent may have made an unexpected decline, or the child may have just been oblivious to the changes in the parent's demeanor as they progressed in their disease. Either way, this is still an important opportunity to bring kids to a common ground about what is currently happening with their parent's illness. Using real words is very important here. Using the word 'die' may seem abrupt or harsh, but using softer words to disguise the facts will only allow confusion and misperceptions to exist. If we say that "she might not make it", or "we might lose her", or "she could pass away" this does not help children to understand what is really occurring. Later, we might assume the children understood that the parent was dying, when in actuality they just assumed the parent wasn't going to make it home for the weekend, or that she would just stay in the hospital for a longer time (until they "found" her!) Again, stay with the facts: "The doctors have said that your mom's cancer can't be cured. They have told us that they think she is going to die" brings us to the point of our concern and doesn't allow for circular conversations going around the topic. I immediately follow this with another question for kids: "Do you know what it means when somebody dies?" Sometimes kids have had experiences with somebody dying but for many kids, in today's world of hi-tech medicines, they may not have experienced a death. "Dying means the body stops working. A person doesn't eat, or breathe, or have any more pain when they die".

These are not easy conversations to have. Children most likely will start to cry, or they may be unable to express any emotions at all. It is difficult to see them in such emotional pain, and yet, over and over I have talked with adults whose parents died when they were children and they were not told anything. They state that they wish they had known, to prepare and to try to understand beforehand, because most often after the parent dies the other adults in the family are too grief stricken to help the children understand what happened. Likewise, I revisit with children after these difficult conversations. When questioned about whether they wish the information had been kept from them, they tell me that they wish their parent wasn't so sick, but that they would not want that to be kept secret. If possible, have these conversations several weeks (3-4) before the patient is expected to die. In families with multiple children, kids from 7 on up and teens should be given the information together, so opt for a time frame around 3- 4 weeks ahead of the patient's expected death for all of the children.

Much like the teenagers, kids of this age need to be reassured that they will be cared for. Where will the sick parent be from now on? (Home? Hospital? Hospice?) Who will take care of them after the parent dies –a particularly essential detail if this is a single parent family (make sure you discuss this information with the family prior to talking with the children). My experience with kids of this age is that they express their emotions for a time (20 – 30 minutes) but their attention eventually returns to more age appropriate activities (playing, books, video game). Like teens, they need time to process and a break from the high emotional toll.

Children Under 7 Years of Age

It may seem unimaginable to tell young children, under the age of 7, that their parent is going to die. Yet, there are ways to prepare even such young children for the event that will change their lives forever.
We first of all have to remember that, developmentally, children under 7 have a very limited perspective of time. "Forever" to them is tomorrow at 5:00pm. Giving them too much information ahead of time will only serve to confuse them. Generally, when there are very young children in the family and if there is ample time for preparation (days to weeks) I opt for a "back door" approach to preparing children. This entails, first of all, making sure that the children have been told about their parent's cancer. Covering the 3 C's will ensure that they are starting out with an accurate understanding of their parent's illness. Then later, in a separate conversation, introduce the topic of dying, but not linked to the parent's diagnosis. For example, "Remember when your friend's dog died (we saw that dead squirrel in the road, etc)? I was wondering if you knew what it meant when an animal or a person dies. Do you know?" Give children a chance to tell what *they* think it means. Then follow up with the

description discussed earlier ("it means the body stops working, that they don't breathe, or eat, or hurt".) Later, when the parent's condition has deteriorated and it is evident that they are going to die in the next few days, you can revisit the issue of dying and apply it to their parent. "Remember when we talked about what it means when somebody dies? Well, the doctors have said that is what is going to happen to Daddy. His cancer is too strong and the medicine can't make it better. Pretty soon Daddy's body will stop working and he won't live here with us anymore." The difference with such young children is their ability to understand time. Children think of death as an *event*, not a process. Even older children, to some extent, experience this perception. When we tell a child that someone is dying, they expect that it is happening *now,* not that it is a process slowly occurring. So, different from the older children discussed earlier, younger children really only need several days to prepare for this event. (However, if possible, if there is enough time, continue to reinforce to younger children how sick their parent is, that they can't do the things they used to do anymore.)

Younger children don't yet possess the ability to understand how this will affect them in the future; that is, they can't project into the future that this means dad won't be there next year when they start playing baseball or taking ballet. They are not able to comprehend the magnitude of the news they have been told. Young children will often be unsure how to respond to such news. If they are with older siblings, they will watch them for cues as to how to behave, and cry if the other kids cry. Allow them time for tears and encourage them that it is okay to cry, and it is also okay to play when they are ready.

In all of these cases, it is important to remember:

> Children cannot be protected from their parent's death.
> Keeping information from them assures that they will grieve alone.

Giving children information only enhances their ability to cope with their parent's illness and their death. Without honest information, they are making up information to fill in the gaps of what they don't know.

Children's Grief

Do children grieve?
If we don't tell them something bad has happened, will they be protected from the sadness?
Is children's grief different from adult grief?

As a Child Life Specialist, I remember during my internship (many years ago) hearing from an aging oncologist that kids didn't feel pain the same way adults feel pain. Absurd! We all know how ridiculous that mindset is – now – but there was a time when that was a popular misconception. The same belief still holds true with many people about how children grieve. The reality is that many times children's expression of grief is so different from an adult's expression, that people assume they aren't experiencing grief. Let's look at some of the specifics of children's grief and then examine it in more detail from a developmental viewpoint.

Probably the most important facet of children's grief as opposed to adult grief is that children grieve *in spurts.* Adults grieve in a linear way; that is, they get sad about an event or a death, and they stay sad. But children's grief is more cyclical as they only possess a limited capacity for such sadness. They tend to grieve for a short time, and then return to activities or friends that give a respite from the sadness. This can be distressing to older adults (i.e. grandparents) or conservative adults who hold strict views about how children should behave. A child returning to play with toys or a video game 20 minutes after being given news of a parent's death can bring about disapproving looks and comments from adults who don't understand the normal progression of children's grief. As professionals, working with families in these intense situations, we can help facilitate better understanding by presenting a more comprehensive education for adults about the nature of children's grief, what to expect and how it differs from adult grief.

"Developmental Re-grieving" is another common aspect of children's grief. In the cyclical nature of their grief, children will return to how they *view and interpret* that parent's death at different developmental milestones. This relates back to the cyclical nature of children's grief, in that they cycle in and out of their sadness. For example, a young girl who is 7 years old when her mom dies will relate to the aspect of her mom's absence as a 7 year old (mom isn't there to help her get dressed, to comb her hair or tuck her into bed like she used to). But when that 7 year old reaches different developmental milestones – *looks at the world in different eyes* - she will revisit her mother's death as to how it affects her now. As an 11 or 12 year old she will see the changes happening in her body and will miss that her mom isn't there to help her through this eventful time, and will, as she inches toward adolescence, recognize that her mom won't be there to help her with her first date, her prom, getting ready for high school/college. These are not things that a 7 year old conceives of but, as children change, they view the world in a different way. So too, will children revisit an important event that occurred earlier in their life, and reevaluate how it affects them now. In this way, although children's grief occurs in spurts, it can last over a longer period of time than adult grief, as children revisit their loss over a developmental span of time.

The way children understand death and express grief can be evaluated, like everything else, from a developmental perspective.

Infants: Infants will not know when a death has occurred; what they respond to, rather, is the stress of caregivers and the lack of consistency in caregivers. Although difficult when a primary caregiver (parent) dies, it is most important for infants to have a limited number of caregivers who can be consistent in their caring.

Children 2-6 years old: Young children do not understand the permanence of death. Cognitively, they are not able to comprehend the infinite nature of death. They live in the here and now and that is how they relate to events in their life. For this reason, even when children have been told that someone has died and isn't coming back, they will ask (sometimes over and over again) "when is Daddy coming home?" Young children might even repeat the information that their parent has died, but then a few short minutes later ask when he/she is coming home. Encouraging parents and caregivers to give a short, standard answer will help children to integrate the truth about their parent's absence ("remember, we talked about this. Daddy died and he isn't going to be with us anymore"). This may need to be repeated many times (think about how many times kids like to watch the same movies over and over again) for them to understand this new truth.

"Magical thinking" is another pitfall that affects young children as they process their grief. As egocentric as children are, they tend to assume responsibility for their parent's absence ("I must have been really bad for my mom to leave me"). Magical thinking persists through childhood, and it is an especially good reason for truthful explanations of a parent's death. After all, who would want their child to think that their parent disappeared willingly because of their bad behavior?

Children 6-9 years old: Magical thinking continues through these middle childhood years. Although cognitively more advanced, 6-9 year old children may still hold themselves responsible for a parent's absence. They need honest information and reassurance about what has happened to their absent parent.

Children of this age have an evolving understanding of the permanence of death, but it can be very fluid. Much like other aspects of children's maturity, there is no definite age when children grasp the concept of "forever". So there may need to be reassuring reminders (as mentioned earlier) if children ask about a parent's prospective return home.
At this age, children will be also concerned about their other caregivers (if dad could die, then so might mom/grandmother). This is an initial understanding of universality – that death happens to everyone. While it

isn't possible to promise that nothing will happen to anyone else, it is acceptable to tell children that their other parent/caregiver is healthy and they expect to live a long time.

Children 9 – 12 years old: At this pre-teen stage, children have attained an almost adult understanding of death, its permanence and its universality. Even these savvy pre-teens, though, can still have some remnants of magical thinking, albeit it is usually more sophisticated than younger children's thoughts. (I had an intelligent 12 year old tell me one time that her mom having to holler at her to clean her room could have lowered her immune system, thus making it easier for cancer to grow and kill her mom.) Children of this age might have a strong interest in what "happens" to a person after they die…like what happens to the body, what is the morgue like, how do we know someone is really dead? This is a function of their increased intellectual capacity and should be encouraged with honest answers instead of admonishments about the gruesome nature of the questions. After all, these are usually questions that many adults wonder about but are afraid to ask! Lastly, pre-teens are likely to see the loss of the parent in relationship terms, that is, how their life relationships will be altered by their parent's death ('my dad and I used to go fishing every Saturday, this was a very special time for us and now we won't be able to share that time any longer').

Teenagers: For many people working with families, teens are the hardest to help; because developmentally they are the least likely to share their fears and feelings. Teens will grieve the most like adults: they understand the universality and the permanence of death. Their responses often are stony silence, as they are unsure how to respond and honor the intense feelings they are experiencing. Additionally, teens, by nature of their invulnerability and altruism, may feel very violated by a death and philosophically wonder what is the use of doing things right, of getting good grades, etc, if you can die so young? This might be expressed as nonchalance - about everything - or as anger or guilt about not saying/doing something prior to the parent's death. (Allowing the teen open information about the parent's illness and time alone with their parent prior to their death can alleviate some of these feelings.) With teens it is most important to remember that developmentally their task is to separate from their parents. This means that, unlike younger children, parents are most likely not going to be a teenager's main source of support during a time of grief. However, it is important to check in with them and ask them who they do feel comfortable talking with? Are they sharing this experience with a friend (boyfriend/girlfriend), or a coach, aunt/uncle, parent of their best friend? Help them think about a safe person that they would feel comfortable confiding in.

Particularly with teens, it is important to talk about the feelings that they might experience in the future. Obviously they know about the sadness and sometimes even fear, but generally no one discusses the anger that might come about – even towards the deceased parent – perhaps weeks or months later. If teens don't know that anger at their parent is normal (for leaving them, for not being there for a special event), then when that anger surfaces they are going to feel anger *and* guilt about the anger, and will most likely not share it with anyone (after all, how would you tell someone that you are angry at your parent *who died*?) This can leave the teen in a very vulnerable position of intense feelings. Informing them early on that anger is normal can help them recognize they aren't a horrible child if and when those feelings materialize. Trying to help them navigate this experience as a growing-into adult is perhaps the most difficult part of helping grieving teens, for they still need the tender care like younger children but will often retreat at the thought of someone showering too much attention on them.

This is all very hard work. And the reality is, in the hospital, we only get to do bits and pieces of it. We are part of the journey only as long as the parent is visiting the clinic or the hospital, but obviously we can't follow every family home and continue the care after the parent dies. For this reason, helping families be educated about children's reactions to grief and possible resources is most important. Sometimes our work involves counseling the children, but because of the piecemeal nature of this work, it is imperative that we complete the educational component as well with the other adult caregivers (surviving parent, grandparents, etc.) Schoolteachers, as well, need to be involved. Elementary and some secondary schools have counselors that can be of great assistance to children trying to assimilate back into the school routine.

Additionally, there are Children's Grief Centers who specialize in helping children understand, process and honor their feelings of grief. In the United States, the Dougy Center has a training program that is the hallmark of a good children's grief center (www.dougy.org). Grief centers base their program on developmentally appropriate groups, where children learn that they are not the only kids their age who have suffered such an experience, where they learn to understand what it is that they feel, and how to express their grief in a healthy manner. Most of these groups are free to the participants, and are funded by community donors and foundations. These groups can be a great asset for families and if available, referrals should be made for families. If they aren't available, we – as professionals – have a responsibility to encourage families to seek some sort of counseling, whatever is available in their community.

As I've discussed the developmental approach to helping families when a parent is diagnosed with cancer, I hope that you can appreciate the unique contribution that child life specialists can play in assisting these families. By our training and experience, we look at children and assess their comprehension of circumstances in terms of their developmental level. As the medical and psychosocial model has expanded in the last 40 years to completely embrace the unique aspects of pediatric patients (and their siblings), so now do I believe the next frontier is including *all children* who are touched by an illness in the family. As we begin to challenge the previous perception that children don't need to know the facts about a parent's diagnosis or impending death, we will encounter resistance. Overall, though, we will find grateful families and salvaged spirit in the young children that we encounter.

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Books

A Child's View of Grief: A Guide for Parents, Teachers and Counselors, by Alan D. Wolfelt, Companion Press

Children and Grief: When a Parent Dies, By J. William Worden, The Guilford Press

Children Helping Children Through Grief: My Path to Founding the Dougy Center, by Beverly Chappell, NewSage Press

Healing Children's Grief: Surviving a Parent's Death from Cancer By Grace Hyslop Christ, Oxford University Press, USA

How do we tell the children? By Dan Schaefer and Christine Lyons, Newmarket Press

How to Help Children Through a Parent's Serious Illness, by Kathleen McCue, St. Martin's Griffin

Talking With Children About Loss, by Maria Trozzi, Perigee Trade