Hello. My name is Donna Zhukovsky. I’m a professor in the Department of Palliative Care and Rehabilitation Medicine at The University of Texas MD Anderson Cancer Center. Today, I’d like to welcome you to this session on “Caring for Life: Pediatric Palliative Care”.

These are the objectives that we’ll be addressing today. You can see that they’re quite diverse. [Upon completion of this lecture, participants will be able to: identify common causes of death in children; recognize differences of pediatric from adult palliative care; describe types of age-appropriate symptom assessment tools, using pain as a model; and discuss the impact of developmental stage on death understanding in children]

And we’ll do so by first talking about what makes pediatric palliative care different from palliative for adults, looking at symptom assessment and management from the perspective of developmental issues and then conclude by talking about how to talk to children about serious medical issues and death whether it’s their own, their parents’, or a sibling’s.

First and foremost, pediatric palliative care is a family centered approach to care for children and their families who are living with life-threatening illnesses. So you might think how is that different from the care of adults?

Well, with children not only are there physiological and pharmacokinetic differences from adults, but there are also developmental factors that impact a child’s understanding of illness and death which are really key to the provision of pediatric palliative care. And as part of this I can’t overemphasize the importance of educational activities, recreation, play, and communication, decision-making, and quality of life to how one works with children. All of these things are key.

In terms of the family, while family is often involved for adults, there’s a much greater involvement of parents and legal guardians as direct caregivers and decision makers. There’s a --- clearly for developmental reasons, there’s a greater reliance on proxy reporters. For those of you who have kids, you’ll know that often younger kids don’t want to talk or, you know, teens might be particularly recalcitrant to answer questions. And so again, there may be a reliance on proxy reporters. Then, of course, there’s the role of child involvement. Should parents protect their children and not talk with them about these things? Should children be involved in decision about their care or perhaps that of a sibling’s or their parents? And what are the ethical issues regarding confidentiality --- confidentiality and child assent with parental consent for children who do have the capacity for medical decision-making, which, depending on the decision at hand, can actually start at quite a young age. Last, but not least, there’s the emotional impact on parents and siblings. The death of a child is out of the natural order of things and --- and when a child is seriously ill, it really raises not only the need for general support, but specific needs of parents and siblings in order to provide optimal care and minimize their distress as they go throughout this experience.
Now, for adults most of the diseases that might, if you will, qualify somebody for palliative care are relatively common. There’s cancer, there’s end stage heart disease, there’s dementia, for example. In contrast, for children the illnesses are quite diverse and often quite rare. There are many different illness trajectories which make it difficult to know when the transition to the palliative phase is taking place. The duration of the care period can be very variable. So for example, it could perhaps span minutes or hours for a child born with a life-threatening illness that perhaps succumbs in the delivery room or perhaps is born dead. Or it might span years for somebody who has cystic fibrosis and lives into adulthood. Also because these diseases are rare, there’s often a need for pediatric illness specific expertise that is not generally available.

Now one would say do children die? Well, sadly they do. In the United States, it’s approximately 53 – 53,000 deaths per year from birth until age 19...

...being approximately equally divided before the first year of life over the ensuing 17 years. As one might expect in the first year of life among the more common causes of death are congenital defects, prematurity, SIDS, and somewhat to my surprise as an adult clinician, trauma.

So from 1 until age 19, the most common causes of death from life-limiting illnesses can be remembered by the acronym, TTTCCC, coined by Dr. Marsha Levitan. The T’s all stand for trauma being motor vehicle accidents, homicides, drowning, and suicides with the proportion varying depending on the age of the individual with the three Cs being cancer as the leading cause of death at 2,200 deaths per year approximately followed by cardiac disease and congenital anomalies. So again, trauma, a very common cause of death and really changes the look of palliative care because often you’ve not even had an opportunity to meet the patient before death and you’re dealing with bereaved parents and families or perhaps the illness course is quite brief whereas for the others the duration may be more prolonged.

Now, speaking about cancer, the good news for pediatric cancer is that overall the cure rate is anywhere between 70 to 80% and again, the leading cause of non-traumatic deaths. Interestingly, over half of those deaths are caused by leukemias and brain tumors.

Now, in terms of illness trajectory, if one thinks of cancer in the adult population, it's fairly predictable. There's usually a plateau and then a rapid decline. For other diseases like CHF in adults, you might see a stuttering course where people decline then stabilize for a while on a plateau, decline again. For children, there are a variety of illness trajectories as well outlined by this article by Hynson and Sawyer. So there are those diseases that are potentially curable, such as malignancies in children. There are progressive conditions where intensive therapy can prolong and enhance life, such as cystic fibrosis where now children are living into adulthood. Then there are the progressive conditions where there isn’t curative or disease altering therapy, but one can focus on quality of life, such as the neurodegenerative conditions. And last but not least, there are conditions which are not progressive but commonly are
associated with complications that may result in loss of life before adulthood. An example of that would --- might be prolonged seizures or respiratory failure from severe cerebral palsy.

Now when you look at this family here, and this is just one family, you can see that there are a variety of ages and stages of development so clearly they're --- they're in different parts of the likes --- life cycle and they're going to have different needs. And keep in mind again that palliative care is for the patient and family. So as the clinician, one really needs to address the needs of all these individuals.

And just to concisely summarize the literature that’s out there, what we know from talking to patients and families a lot of this from qualitative work as well as quantitative studies is that families value good pain and symptom control. They value direct, sensitive, and clear communication appreciating the influence of culture on that. Very much value caring relationships and when the parent considers it to be age appropriate, they want child involvement including an end of life decision-making. So it’s not the age of the child that determines if it’s appropriate, but rather how the parents view the child’s involvement. Another key theme is healthcare professional availability 24/7. It's really scary to be out there and have no one to call who is familiar with your child and who knows how to address the different symptoms or challenges that may come up. And in keeping with the value placed on caring relationships, these families really want a continued relationship with healthcare professionals even after the child’s death. They develop a very --- often develop a very strong alliance with the healthcare team and when this relationship stops after the child’s death not only have they lost the child, but they feel like they’ve also lost the support system --- this huge support system that’s become very important to them. I was at a meeting with some bereaved parents and other clinicians were there and the nurses were saying to the parents, "Well, we feel like we might upset you if we call" and this one mom turned around said, "Do you think I forget for one moment that my child has died? Please call us." So I think that sort of puts it in a perspective for us who are concerned about perhaps distressing the parents.

Now, where does pediatric palliative care happen? I think really the point of this slide is it happens wherever the child is whether that’s at home, in the hospital, in an inpatient hospice setting, or out there in the community. So when we think about kids at home, where is their community? If they’re of school age as they are for the vast majority of their childhood that community, those are their peers, their friends in school, their teachers, their classmates, etc. So we want to keep that in mind when we’re envisioning their --- their world if you will.

Okay. In contrast, they tend to die in the hospital and much less commonly in the home. And in the hospital, it might be in the neonatal or the pediatric intensive care unit, on a hospital floor, in the operating room, or in the emergency room. And again, if you think about the causes of life-limiting illness in children, trauma, and other things playing into it, you can see why those are common sites of a death.
Some of the reasons relate to the suddenness of traumatic death, prognostic uncertainty with various diseases, or the rarity of diseases so that people really don’t know what to expect. Then, it’s compounded by the difficulty of decision-making on behalf of minors or in conjunction with minors. For children, who have neurodegenerative conditions, many are maintained on mechanical ventilators and --- are maintained on ventilators and there’s the difficulty of transporting ventilated children home. And then for some parents, not all, there is the will --- unwillingness to forego life-extending therapies and for some it may be appreciated as perceptions of abandonment or belief in miracles of medicine and God. So are all sociocultural phenomenons that we need to factor in when taking care of our patients and their families.

As mentioned earlier, there’s the long-term relationship with the hospital-based team making it difficult for people to move back home. They’re often treated at centers, you know, distant from where they live. Fears of inadequate symptom control out in the community which is not surprising given the limited availability of pediatric palliative care experts in the community. Then, there’s the poor fit of hospice with life expanding ther - -- therapies and limited reimbursement for many of the necessary service --- services. So you can see that there a whole host of factors that can work together to make it simpler to keep patients in the hospital. Whereas if --- if you look at the data that show where patients --- where children and their families say they would prefer to die the vast majority will tell you that they’d rather be at home.

And so here you can just see, this is one model of supportive or palliative care. It’s not limited to children but weary --- really where palliative and supportive care starts at the time of diagnosis or some would even say during screening and investigation and then just is integrated through with disease dire --- directed therapies as they’re available on into grief and bereavement should the child die.

Now, in the next session of this talk what we’re going to look at is some of the developmental issues that make pediatric palliative care different from that of adults. There are the types of pain that we see, some of the assessment tools that can be used, management st --- strategies, and a little bit about developmental pharmacology.

Now at diagnosis, close to two-thirds of children with cancer excluding CNS tumors have pain. So it often leads to diagnosis. Median duration being 74 days prior to cancer treatment and it --- interestingly it’s not i --- influenced by disease extent. So kids with early stage disease are just as likely to have pain at diagnosis as are children with more advanced disease. Thankfully, there’s rapid les --- resolution of pain for many with the initiation of cancer treatment. And this is seen more common with the hematological malignancies than the solid tumors because they tend to respond more rapidly.

Now in terms of the etiology of pain in children with cancer, we know there’s --- it can be related to treatment, it can be related to procedures, to the tumor itself, and as with adults for causes unrelated to cancer.
And you can see in this study here that close to 50% of children reported pain related to the --- the treatment itself, be it chemotherapy, radiation, or surgery followed pretty closely almost 40% with pain related to procedures with the lowest percentage being pain due to the cancer itself. So that’s a little bit different from the data in adults.

Thinking about procedures in kids. Needles. We don't think about phlebotomy, blood taking, as a source of pain in adults, although many will complain about it. But for children, this can really be a major deal and they are ways to prevent it and minimize it. Bone marrow biopsies, central line removals, or insertions for that matter, and diagnostic procedures, so some of these may seem kind of minor if you were thinking about an adult, but for children they take on much more weight if you will.

So as we said before, almost 40% of pain relates to invasive procedures. The need for repeated procedures is common. So a proactive approach is really important. If you don’t get it right the first time, that child isn’t going to want to follow through with tests and procedures from there on. So from many different perspectives both from quality of life and for need for repeated procedures, it’s really important to get it right the first time.

Chemotherapy. Some of the treatment-related pains, myalgias, mouth sores, extravasations with --- of chemotherapy with skin irritation, neuropathies, the pins and needles that one sees with many of the chemotherapies, and then all the complications of graft-versus-host disease for children who have had allogeneic bone marrow transplants. Some of the treatment-related pain syndromes we see in children who have had surgery are just post-operative pain and phantom limb pain, some of which can be prevented with preoperative regional analgesia. And then with radiation, mucositis and dermatitis are common depending on where the radiation takes place. Diarrhea actually can be very painful too, if you have radiation associated diarrhea that’s frequent with associated cramps.

Now, as for adults, when we’re thinking about symptom assessment, we really want to think about the multiple domains that influence symptom expression. So this was taken by analogy from the multi-dimensional approach to pain and pain re --- expression so there are all the medical factors, the tumor, the treatments, procedures, what have you that may gene --- generate the nociceptive influences that cause pain. But then there are social, psychological, and spiritual factors which influence how the individual perceives that pain and, therefore, how it’s expressed. Social fam --- factor: if the parents don’t have the finances to purchase the medications needed for symptom control that’s --- that’s a reason for poorly controlled pain, for example. And yet we often don’t think to ask, do you have, you know, the resources to get this treatment that I’m prescribing. Psychological: if the parent is fearful, the child’s much more likely to be fearful and that can impact pain expression as opposed to if you have a calm parent who is able to distract the pa --- child that may attenuate some of the pain that’s experienced. And even young children as you’ll see later on have --- can have a sense of spirituality and are in different stages of spiritual dem --- development. And for those
who think perhaps they’re being punished or what have you, that may exacerbate how
the pain is experienced or the other symptom whatever it is --- whatever it may be.

Now, in terms of assessment tools, there’s really two major kinds. There are symptom
surveys or tools that assess a whole host of symptoms at one time. And then, there are
tools that evaluate specific symptoms sometimes just for intensity but often in multiple
dimensions.

Looking at children, some of them are preverbal. So if you look at a 1 or a 2 year-old,
even if they have a few words or sentences, they’re not going to be able to tell you
necessarily about their symptom or tell you in any great detail. So there we really rely
on behavioral scales. As children get older, we have the opportunity to use categorical
scales, numeric rating scales, and visual analog scales. And I’ll --- I’ll show you some
examples of these in a moment. Scales may be uni- or multi-dimensional. So in other
words, they may measure only one part of the pain, one dimension rather. So it might
be intensity, it might be quality, it might be associated to stress or they may mel --- mul -
--- measure multiple domains and then we would call that multi-dimensional.

Now, clearly with kids, a 1 year-old is very different from a 16 year-old. So it’s important
to use age and developmentally-appropriate scales. Recognizing that when using
behavioral scales because the child cannot self-report, it may re --- under represent the
intensity of persistent pain if --- you know as compared to what the child could tell us
him or herself. Okay.

So for children under the age of 4 or those with developmental disabilities that place the
children in that type of developmental span, we really rely on behavioral observation
scales since they aren’t able to self-report with any kind of detail, if at all. Once children
are between the age of 3 to 7 years, we can really start using faces scales whether it’s
by photograph or a drawing, color analog te --- scales such as pain thermometers
where the cooler colors, the blues represent lower intensity of pain and as it gets fiery
hot stronger intensity of pain, body maps and the po --- poker chip tool which I’ll show
you shortly. Then, by the time children are about 8 or older, they can really fall back on
using some of the adult versions of visual analog scales, horizontal ones unlike the
vertical pain thermometer, and verbal rating scales where one might say, “Oh, I have a
little bit of pain, a medium amount, or a lot”, for example. That would be an example of
a --- a verbal rating scale.

So CHEOPS or Children’s Hospital of Eastern Ontario Pain Scale is an example of a
behavioral scale. Then, there’s the Gustave-Roussy Pain Scale, the poker chip scale,
the faces scale of which there are several versions, the pain thermometer scale which I
just mentioned, and then you can ask kids to rate pain numerically. In adults we’ll ---
and in older kids, we can use a zero to 10 scale and in younger kids really we might just
go up to 5. So to use a numerical scale --- a numerical rating scale the child has to
understand the concept of proportionality and that’s where the age comes into it.
Here you see an example of the poker chip tool for pain developed by Hester. And so you can see those four poker chips and what the clinician does is tell the child here are four pieces of hurt and I want you to give back to me the number of pieces of hurt that you’re feeling right now. That would be one way to do it. So the child you know trades --- trades chips with you to show you how much they hurt. Again, that sense of proportionality.

This is an example of the Oucher scale which is a photographic scale with the child at the bottom sort of having a neutral face not having any pain and as you can go up the scale, you can see from the grimacing that the --- as you go up, the child seems to have more and more scale and you --- pain rather. And you can associate numerical values with these pictures, so that if you’re a researcher or even a clinician who wants to enter data into a database numerically each of these is assigned a --- a number. It’s important when you’re using any kind of faces scale whether it’s cartoon-like or a photograph such as you see here to take --- to try and --- when they develop --- design these scales they try to remove the component of affect of emotion and just keep it to the facial grimaces and clearly there’s also a cultural component. What you see over here on this, this is an example of a numeric rating scale. And this one actually goes all the way to 100 but again in children --- younger children you might use 0 to 5 and in older kids 0 to 10. You wouldn’t expand it so much.

Okay. Now I’m going to touch briefly on the Memorial Symptom Assessment Scale which is a symptom battery so it assesses multiple symptoms and it’s also a multi-dimensional tool. And there are two pediatric versions, both of which were derived from the adult version of the Memorial Symptom Assessment Scale. In the adult version, it’s self-report of 32 symptoms looking at both the physical and the psychological domains. And in those domains, it’s a multi-dimensional tool because it looks at frequency (how often it happens), intensity (how much it hurts or how strong the particular symptom is), and the associate --- associated distress (how much does it bother you, for example).

So Dr. John Collins, who is a pediatric oncologist and palliative care specialist in au --- Australia, initially developed the Pediatric MSAS 10-18 for children in the corresponding age range. And they found --- his group found that these children could evaluate 30 symptoms. So not that much different in terms of number of symptoms from the adult scale which was 32. You’ll see that some of the words are different, the words used to describe the symptoms. Whereas younger children from 7 to 12, and so there’s some overlap between these two age versions, could rate eight symptoms. So you get less information, but this is what they were able to do at their age and --- stage of age and development.

Okay. So what I want you to take away from this slide are two things. I don’t want you to memorize the frequency or the prevalence of these symptoms, but rather to see that multiple symptoms are common. If you look at the older kids, lack of energy, which we would call fatigue in adults, pain, feeling drowsy, nausea, etc., all very common. And you can see here that the words are somewhat different than you might use for an adult. So an adult, you know, it would talk about depression and here it’s feeling sad. Feeling
nervous and worrying being surrogates for anxiety. The younger kids 4, 5, 6 --- actually have all eight symptoms here that are evaluated. And again, you can see that multiple symptoms are common. So that’s really the take home message. Often for these children symptoms don’t come in isolation, but in a pack and unless you ask you’re not going to find out about it.

So now I’m going to move on just very briefly to touch on some of the modalities of pain control. And this is not all that much different than modalities in adults. And I’m focusing on pain both with the assessment tools and the management strategies because that’s where the data are most developed. But you can use similar strategies and approaches for the other symptoms. So whenever possible treating the underlying cause, so disease specific approaches. If a person has back pain because of spinal cord compression, treating that spinal cord compression with chemotherapy if it’s chemotherapy sensitive or with surgery if --- or radiation depending on what it’s most sensitive will help relieve the pain. Pharmacologic modalities of pain control when one is waiting for disease specific interventions to take effect or if there is no disease specific therapy that’s effective. Anesthetic techniques, so a variety of nerve blocks for example. Surgical techniques, if somebody has bowel obstruction and the surgeon is able to bypass that blockage, the pain goes away. Techniques of neural augmentation, for example, TENS (transcutaneous electrical nerve stimulation). Physiatric means of pain control are frequently neglected. And here we really rely on our rehab colleagues and physical and occupational therapy to help people learn positions which are most comfortable for them when they’re mobilizing, orthotics to stabilize painful movement-related back pain, or perhaps a prosthesis for somebody who has stump pain or phantom limb pain. Cognitive behavioral techniques are key here and really are a very --- can be a very useful adjunct to pharmacotherapy and other techniques noted here because they rarely have overlapping side effects. They don’t make people sleepy. They don’t make them constipated. So there’s a whole host of cognitive behavioral techniques that one can incorporate and while some require very specific expertise, there are others that can be done with very modest training by the bedside nurse or physician. And last but not least integrative medicine. I think there’s a burgeoning literature that shows us that adult and child patients’ families are using these all the time. They may not volunteer it. So it really behooves us to inquire about their practices and to keep them in mind as possible complements to therapy here so this might include dietary maneuvers. It might include acupuncture, massage, relaxation techniques. So there’s a whole host of techniques here too.

So as mentioned earlier pharmacotherapy is a mainstay of treatment.

These are the drug classes involved, very similar to adults. The difference is in understanding the dosing and we’ll talk about some of the developmental issues in a moment.

In terms of cognitive therapy, I just wanted to touch on this ag --- for another moment. It --- Cognitive therapy is a way to change distorted or unrealistic thinking and make it
more --- more beneficial to that person. So for example, if you go into a procedure saying you know this really hurt last time and it --- it's just going to hurt like all get out and the child is crying and tensing up his or her muscles, well that's --- that's probably going to make things a lot worse. Whereas if you can get them to take their mind off of it and --- and distract them and instead of saying I know it's going to feel really awful, you know, change it to a different thought process that can influence their physiologic responses and moderate the pain influence.

As for adults, for continuous pain regularly scheduled analgesic with prn doses as needed. You use those prn doses to titrate when you don't know what the person needs to prevent anticipated breakthrough pain. So if you know going to physical therapy or going to play is going to hurt, you know, causes flares up the pain then take a breakthrough dose about a half an hour before so it's in the system and working when the child needs it. Going down to radiation, all that movement associated with pain give them a breakthrough dose before. And then, of course, we use rescues for control of bake --- breakthrough pain.

Now here and this is what's a little bit different from adults. For procedural pain in children with cancer, there's a lot of preparation involved so you want to prepare both the child and the --- the parent. And here child life specialists can be very helpful. These are Masters prepared individuals who have a --- their education is in child development. So they understand how children think at different ages and then they can help in an age appropriate manner walk these kids through the procedures. They might use something like dolls that have ports where you can show them how the port is accessed or you --- they can walk the doll through a procedure, you know, who is going to have a bone marrow or something like that. So preparation is key and I think this is something that's easy to overlook especially if you weren't trained as a pediatric provider but you're an adult trained provider working with kids, which happens quite often. Then provision of adequate analgesia and this is all part of getting it right the first time. And that analgesia might be systemic or it might be topical. So for example, if you're going to access a port or do a blood draw in an adult the venipuncturist would j --- the phlebotomist would just --- would come and do it. Well, in a child, you want to use EMLA cream and that takes a little bit of preparation. And you need to leave it on for a while and then come back and do it. So you need to build all this into your approach and then keeping in mind physical modalities as we mentioned a moment ago --- earlier physical therapy, massage, heat, etc.

Using those cognitive behavioral strategies, think about distraction. Nowadays when people go to the dentist, right, they often get those headphones with movies so that they're not paying attention to what the dentist is doing. I think this probably first started with kids so, distraction, attention, imagery. You can have them visualize themselves being in a situation that they really enjoy and playing a game, for example, and maybe one that might mimic some of the sensations they would experience. Play therapy, art therapy, desensitization. So here is where you really need some help with people with specific expertise and, again, I can't emphasize enough the importance of child life specialists. And then last but not least, when appropriate conscious sedation. So for
adults bone marrow aspirations and biopsies are --- are typically done with just local anesthetic, whereas, in children, they’re often done with conscious sedation. So keep that in --- in mind as well. So you want to pull all this together to proactively treat procedural pain. Okay.

Now, we’re getting down to the end. We have a little section on developmental pharmacology and then we’re going to talk about how to talk with children about serious medical illness and death. So in terms of developmental pharmacology, I really refer you to this article by Berde and Sethna in the New England Journal of Medicine. I think it’s quite seminal in how it explains things and really what they look at our differences in body compartments, plasma protein binding, hepatic enzyme systems which are used for drug metabolism and then renal filtration and excretion of drugs. Those are sort of the four main categories.

So think about babies, neonates. They’re kind of soggy and squishy. They’re kind of round, right? They’re not elongated like a toddler or you know an elementary school child. They’re round. So they have less body fat and muscle and more volume of distribution of water than older kids. You know they’re --- they’re squishy when you hold them. You’re likely to get wet. So they have an increased volume of distribution of water soluble drugs. And so for drugs that are water soluble there may be a greater duration of action and that translates into a longer dosing interval. You don’t give it as often. So for example, you might give a jug every six hours instead of every four hours in an older child for water soluble drugs.

Neonates also have decreased concentrations of plasma binding protein, such as albumin and that means for drugs that are protein bound since they have lower amounts of protein binding in --- in the blood, they have a larger fraction of unbound or free drug, the bioad --- biologically active component of that drug. And so there’s more drug available which increases the drug effect and/or the toxicity. The implication being, (oh, well, it wasn’t on the slide), but the implication being that you for these drugs might need to give smaller doses of drugs --- of that drug.

Neonates and infants also have an immature cytochrome P-450 system and same for the glucoronyl transferases. So for drugs that are metabolized by these enzyme systems, again, you’re going to need a smaller dose for the same effect relative to children and adults. Because it’s not broken down as quickly, it stays there longer. It’s as if you’re giving a bigger dose. Interestingly, and I find this really intriguing, children in the age range from 2 to 6, the hepatic mass relative to kilogram of body weight is higher than it is for adults. So they can clear drugs more rapidly than adults can for drugs metabolized by the liver. So they need bigger doses than adults. This is all really interesting. So again, clinically neonates and infants, we need decreased infusion rates and increased dosing intervals. Children 2 to 6 years, we might need higher infusion rates and longer dosing intervals. Again, all bec --- needing to know where the drug is metabolized and how it’s affected. And that’s why it’s always great to talk with your pediatric pharmacologist. You don’t have to figure this all out by yourself.
Now looking at the kidneys, again, not surprisingly in neonates and infants the glomerular filtration, the GFR, is lower than in adults. So again drugs excreted or metabolized by the kidney are going to stay around longer. You need lower infusion rates, longer dosing interval. So you can sort of hear this theme again.

Now we’re getting up to the --- the brain and partitioning --- partitioning between the CSF and the blood or the brain and the blood. So one issue and --- in this partitioning is the permeability of the blood brain barrier which we know may be changed by tumor if there’s brain metastases or a brain tumor for example. But changes in protein binding may also influence the balance here. So again, important to keep in mind, levels of protein binding in the bud --- blood and how much bio --- what proportion of drug is --- is available as free or the bioavailable component to diffuse across the barrier. And again, being very familiar with the pediatric pharmacologist or having one to connect with is --- is key here.

Okay. Okay, that was the hard part. So now we’re going to talk about another difficult part and that’s how does one talk with children about death and dying. And these are the areas that we’re going to touch on.

Okay. There are many myths and misperceptions about how young children think about these issues. And it all comes out of concern for them and wanting to protect them. Many people think that young children don’t grieve. People often think that children, adolescents, and adults all grieve the same way. And no two people grieve the same way, but it’s actually quite different or how it’s expressed is different depending on the age and stage of development. Many people think that children will be traumatized by watching a loved one die. Whereas in reality, if the child knows what’s going on, has been given the opportunity to ask questions in a safe environment, and gets age appropriate responses, if that person --- if that child wants to be with the person who is dying, they actually do better. So you have to see what the child wants. People will --- Parents will often say, “Oh, my child doesn’t know they’re dying”. I’ve heard many parents say this. But if you talk to that child separately, they’re holding back a lot of fears and concerns because they don’t want to distress the parent. They’ve seen their friends die, their peers at the cancer center die. They know what’s going on. They see that their body is changing. And again, this belief that children should be protected from death, but it --- you know, is that really possible?

So this doesn’t affect just children with cancer themselves. It affects the child’s community, so their friends, their peers, their cas --- classmates. It affects their siblings as well as the children of adult cancer patients. And so you know, even for those of you who treat largely adults or exclusively adults, they have children and young children and --- and grandchildren and so these children need attention and our care, too.

So I think you’ve probably seen from my comments a moment ago that the data --- that I --- that my bias is and because the data support, that kids really should know that they’re dying because, again, otherwise they’re holding onto all of these fears without
an opportunity for people to support them. Should they see a parent or sibling die? Again, it depends on their preferences. Should they help plan the funeral? Yes, if they want to. Should they go to the visitation or the funeral? Yes. Again, offer them the opportunity if they want to. If they don’t then make other arrangements.

How do you plan for kids that get overwhelmed at the funeral? Well, what you do here is you recognize that if you’re the bereaved spouse, you may not be able to give your full attention to your children because of your own grief. So have one adult there for every affected child. So if that child’s need changes, that child will be cared for and can leave with somebody safe and caring, so that everybody gets their needs met at the moment. What about kids that struggle with anger at the dying person? Letting them know that it’s okay for them to express that.

So in general, what’s known is that open communication helps diminish emotional distress. So this is the exact opposite of when many --- what many people think. The information needs to be developmentally appropriate. It needs to be delivered in a sensitive manner. And again, it should encompass all the children affected by cancer so it --- whether it’s their own illness, that of a sibling’s, a friend, or parent or other important relative.

Now some of the core concepts --- to death under --- to a mature death understanding or --- the four concepts necessary for a mature death understanding are irreversibility (that once it happens, you don’t get undead again like a cartoon character), finality (that all systems stop – grandpa doesn’t need to pee after he’s died and been buried), that it happens to all of us universal --- universality --- universality – to all living things, animals, and here --- here if the child has had an experience with a pet --- a loved pet that is a way to help explain to some younger kids what’s happening with the person they love, and causality that it’s not mystical. There is a reason. We may not always know what it is still in this day and age, but there’s a reason for this happening.

Now, this is taken from an article by Himelstein et al. in the New England Journal and this --- this is the other article that I would really encourage you to take a look at and you can see that in very young kids, say up to about the age of 2, they really don’t have a concept of death. Their world really is sensory and motor. It’s what they see and experience. So they might sense that something is wrong but they really don’t have an understanding of --- of death. And --- and their spiritual development is really their trust and hope in other. And so what we can do for children in this age range who are affected by dying is really give them maximal physical comfort and stability. Give them comfortable, familiar objects, favorite toys, and just simple physical communication. Hug them, hold them, play with them. When kids get a little older until to about 6, this is a very egocentric age and magical age, it’s all part of normal development. There’s nothing wrong with them, but they think if they think something it happens. They’ve got the power if you will and they’re just first developing language skills. So it’s in this group where they really think that death is temporary, that you --- you die and then you get undead again. You sort of go to sleep and you wake up. You die and you un-die. They don’t realize it can happen to them and as I mentioned a moment ago they --- they think
you know say they got --- they got mad at mom because she gave them a timeout for whatever and they wished mom dead at that time. If mom then goes and gets cancer and dies, they might actually think that it was their fault. While as adults we think how could they possibly think that, in reality this happens a lot and that’s why it’s so important to make it safe and let them talk and ask their questions. It’s why you want to use the real word ‘mom has cancer’ and it’s why you want them to feel comfortable to answer --- to ask questions so that you can relieve them of these misperceptions. Faith is magical. Participation in ritual becomes important. It’s important to them to have courage. And in this group, what you can do is you really want to as much as possible minimize separation from parents, correct perceptions of illness as a punishment, try to make sure you know, check out if they’re feeling guilty, and use precise la --- language, “grandpa died”. Not grandpa went to sleep because then they might be afraid to go to sleep. They might not wake up again or you know don’t say, “Daddy went to the hospital because he’s sick” because then when dad dies if they get a stomachache and they’re sick they might think that they are going to die. So it’s really important to use clear language and precise language.

As people get a little older so sort of a little older than 6 until 12, they have very concrete thoughts. They’re starting to make that shift to an adult understanding of death. They know it can be personal. They really want to know all the minutia, the nitty gritty of why things are happening. In addition to being concrete, they’re kind of absolute. So things are right or wrong. And they really connect ritual with personal identity so you want to help them create some rituals. So in terms again of interventions, eval --- evaluating their fears of abandonment, being truthful, giving concrete details, if requested. You don’t need to go into a lot of detail but the amount of detail they seem to want. Validate them for their efforts to --- to master things, make sure that they have access to their peers. You know, that they’re still getting to see their friends, go to school if at all possible, and let them participate in the decision-making. If it’s for self, you know, even a young child can make the decision in which arm should they have the --- you know the blood drawn or as they get a little bit older, you know, some can really even participate in decisions about chemotherapy. They can quite clearly articulate that they might want to continue chemotherapy or maybe they want to stop because they --- they just don’t to feel sick anymore and --- and that’s with the understanding that they’re going to die. So little kids are pretty wise. And then as children get older, you know, so adolescents and teens they really become much closer to a --- an adult understanding of death. It becomes more abstract. They sort of look into some of the non-physical manifestations, more of a relationship with God or a higher power, and really looking for meaning and purpose in life. What is their value? What have they meant to other people if it’s their own death that’s coming up? And here really key is reinforcing that person’s --- that child’s self-esteem, allowing them to express strong feelings, allowing them some privacy, promoting their independence, again access to peers, and again allowing them to participate in decision-making. And here that’s sometimes where you see those struggles between, you know, maybe when the child wants one thing and the parent wants another and how do you deal with that as a clinician.
Now, some ways you know where a child is at in their death understanding is by the questions they ask. So if they say, “When is my dog coming back to life?”, you know well they haven’t really mastered irreversibility. If they don’t understand that, then they can’t really mourn. They need to detach to mourn. “Do dead people get sad?” That’s probably a little bit more abstract than “how do you eat underground” but it’s the same kind of thing. They haven’t really grasped that when you die everything physical stops. Universality. “When will I die?” Well, that to me might suggest that they’re getting an understanding that it can happen to everybody but, “Do I have to die?” “Do children die?” “Does everyone die?” They’re still struggling with that. Again, you want to help them understand it so that they don’t take some of these misperceptions that may be developmentally appropriate, but not helpful to them. 

And then causality, which is when people really get an understanding of --- a realistic understanding of why death is happening, if they say, “Can I wish someone dead?” Well, they haven’t quite understood that yet.

Adults tend to grieve in sort of a --- a slope, you know, so they --- they --- they grieve pretty steadily. Children tend to grieve more in waves. So, it’ll be a very intense behavioral expression. They might be crying and being inconsolable and then the next minute, they say, “Can I go outside and ride bikes?” And that’s not because they don’t get it. It’s how they cope. So their manifestations are different. So it’s very intense in waves and then they sort of go back to play or whatever their activities are. So it tends to last longer and they tend to have to do the work of grieving at different developmental milestones. So for example, say, a child died --- a parent died when the child was in middle school. So when --- when the child graduates middle school, when the child graduates high school, when the child graduates college, if the go to child, when the child gets married or has their first b --- baby at each of those times, they may need to revisit and typically do revisit the work of grieving because they have to integrate it into their more mature self if you will. It’s impacted by multiple factors, but the key one being really how well the family is doing. If the family is a stable family that relates well and can talk, most kids do okay.

Other things that influence grief, age and developmental stage, personality, what were their previous experience with death, the relationship with the deceased, how close was it, and then the parental style of coping with stress.

We mentioned patterns of interaction and communication within the family, how the child’s care needs are met, availability of consistent relationships with other adults. So if the parent is really too maxed out caring for, you know, the ill child or caring for their spouse that’s okay as long as there’s another caring adult whether it’s a relative or the parent of a friend who can step in and provide that consistency. And then some believe also the presence of a faith can be helpful.

Okay. Now, in terms of informed consent, parental permission and pediatric assent, so only children 18 and older can give consent. So for children under 18, you’re really talking about pediatric assent. The child really has to say, “yes,” with an understanding of what’s going to happen, what are the consequences if they do or if they don’t, if you
will, and also requires parental permission. So the American Academy of Pediatrics of Committee and Bioethics fully supports child involvement and pediatric assent. So they’re in the process of becoming intelligent, observant, capable, and responsible persons. And so they really should be involved in the flow of decision-making responsibility including their assent to the greatest extent possible.

So to summarize, the framework for discussion is age and developmentally appropriate, sensitive delivery, respectful of cultural and religious beliefs, a safe environment conducive to open expression of feelings and thoughts, presence of a strong supportive adult.

All of this is thought to decrease anxiety and emotional distress in the child and parent. There’s a Swedish study that shows that there’s less parental regret if there’s been open dialogue. It allows for correction of distorted beliefs. It acknowledges the reality of death as a prerequisite to successful grieving. It shows the parent’s confidence in the child’s ability to cope and really supports them as a full family member.

So the take home points from today are really that the rarity of pediatric death and the associated --- that pediatric death and the associated causes are rare other than trauma and so there’s a limited availability of specific expertise and that really complicates the care process. The disease trajectories are different from those in adults and they really vary from very, very brief to quite prolonged often with an unclear transition to the palliative phase so one constantly has to be on the alert of when is the time right, the importance of developmental impact on communication, understanding of illness and death, and on pharmacotherapy. So these are all areas we’ve touched on.

There’s a greater involvement of family than for most adults with a different kind of emotional impact. Assessment as with any kind of palliative care is key to optimal care and requires input from all key stakeholders. So you really need to hear from the children as well as from their parents and other people in their lives. And when available because there are adults --- a dearth of age and developmentally appropriate symptom assessment school --- tools, we need to use the best that are available.

Incomplete death understanding may lead to potentially harmful misperceptions that can last for years. Parents really want direct healthcare professional communication with their child whenever they consider that to be appropriate and that pediatric assent should be included to the greatest extent possible.

And with that I’ll stop with this picture drawn for me by an 8 year-old that I had the privilege of taking care of. And we’d really welcome any feedback that you have on this session so that we can improve it for future versions. Thank you.