

Paula



Mother of Luke, age 11, and Lydia who died from cancer at age 7.



A LONG INDEFINITE TIMELINE

Just because your child is seriously ill, doesn't mean you stop parenting and teaching them.

<https://youtu.be/U68NP9df0MY>

Paula: I think parents of such children do try to keep things as normal as possible. I remember being in awe at the hospital of a mother of like a one-year-old. Just because your child is diagnosed with cancer doesn't mean you stopped teaching them how to speak. Just because your child has a disease doesn't mean you stop telling them what's right and what's wrong. You don't stop being a parent. You don't stop teaching them what you would teach them if they were going to live because if they do live and you've spoiled them rotten, you are going to live with that consequence. You know, so you're still are going to say no and mean it.

Paula: It is because not all children die. And if they are going to live, you are going to want them to know how to live with other people. And if they just get the answer yes all the time, yes, because you are dying, you know, and it's not going to work if they live.



FINDING SUPPORT

Have at least one person you can reach out to.

<https://youtu.be/Gc3G27yAfHg>

Paula: I know for me there was always one person, one woman from my church who was always been by go-to. If I'm having, like, the worst day, she is kind of like my prayer partner. I call her up and say, please can you pray for me because I don't think I'm going to make it through the day if I don't get some supernatural strength or something. So that was helpful. And if you are not a believer, maybe just have one person you can call and complain to or somebody who you know will boost you up when you are down, who can like remind you of all the good thing you've done even if you feel like today you did something wrong, or just you know, have at least that one person that you can reach out to.



DECISION MAKING AND PALLIATIVE CARE

Pediatric cancer means that we give these children medicines that are just so damaging.

<https://youtu.be/XLMpS6nbhKA>

Paula: So the doctors had given us three different trials or protocols to look through and decide which one we wanted to try next with Lidia. Do I want my daughter to possibly lose her fingernails, lose her teeth, you know, have bones that won't grow and perhaps never grow beyond this size because this may kill the cancer. It was -- you know, there was not a good choice among which protocols to use. That's the most difficult thing about pediatric cancer are there are not many available treatments and many of the medicines that we give these children are just so damaging, even if they do live.

But it was one of those things I think we would just kind of give her some information, but not all information, because it was too much to take in. I mean, you would never want to take any of those medicines knowing what the side effects could be, you know, it was hard enough in the first protocol of chemotherapy just thinking my child is going to lose her hair, my child may never have children. You know, just all those things, it's like you end up grieving little pieces of their life as each thing becomes clear that, you know, having children will no longer be a possibility or what have you.

There was one protocol that they brought up like three times. I was angry by the time they brought it up a third time, because I was like, it just had the most horrible side effects possible. And I'm like I don't want to see this one again. Sadly in the end, we ended up giving her that exact protocol because it was the only treatment left. And at that point, it was nothing or the most horrible treatment you could think of with, just the side effects. It was actually easy to take. It was less stressful. She didn't get nauseous. You know, her -- I don't believe she had to have blood transfusions with that one, but that was the one that had the side effects that you could lose your teeth., You could -- your growth could stop in its tracks right there. And those were like, really difficult, but you'll try anything when you want to save your child.

They gave us the strength to say Yes to what needed to be done.

<https://youtu.be/jHTNxH8BXc4>

Paula: in the end we sat down. Lidia was in the hospital for approximately five days. She wanted to go home more than anything in the world. And I just felt it was good like her whole team was there. Even some of the nurses from the Jimmy Fund Clinic came over to children's hospital to be part of the discussion. And we all talked about all the possibilities, you know, the worse case scenarios that could happen if she came home. This was -- we know that -- we do know that would be the last time that she'd be coming home if she came home. And I think our conversation with the whole team helped us to decide to do what was the right thing for Lidia. And although they gave us all the worse case scenarios, I think they also gave us the

strength to say yes to what needed to be done to, you know, to do the best that we could for Lidia which was bring her home.

I know we'll spend the eternal day in heaven together.

<https://youtu.be/yeOrQikVClo>

Paula: so all those things when you are hoping and praying for a miracle and you really believe that miracles exist and then you don't get that miracle, it's difficult. It's really difficult. But in the end, I think what saves me and my faith is that I've always said my greatest prayer for my children is that we'll spend the eternal day in heaven. And if Lidia is already there, then I guess my greatest prayer was already answered. She may not be with me here now, but I plan on an eternity with her. So we'll be okay.



SIBLINGS

The sibling bond was kind of broken by cancer.

<https://youtu.be/mlek4tZnmok>

Paula: My ex-husband would take my son usually when Lidia and I were in the hospital. On occasion we would do a role reversal and Luke would be with me and Lidia's dad would be with her in the hospital. But I think probably as with most sick children, they want their mom, nothing against her dad. So it was difficult. Luke and Lidia were very, very close, extremely close. And it was really hard when that bond was kind of broken by cancer and they were spending less time with each other.

You know, and children go through that thing to, I think, where the sick sibling is getting tons of gifts and cards and attention, and the well sibling is -- it can be a little bit forgotten about by others. And also I think as a caretaker, you sometimes can become like so overwhelmed with checking temperatures. You know, Lidia had a feeding tube. So there was a lot of activity around feeding her. She was on so many medications and the times of the medications that you can get so caught up in that that you spend less time with the other child or children that you have and so it's hard. You know, those transitions come really quickly. And I guess, I'm really fortunate that my ex-husband was able to take Luke most of the time. Luke didn't have to spend time at friends or neighbors or anything. He was mostly with his dad if he wasn't at home.

We didn't want him to have regrets later in life that we didn't include him in the conversation

<https://youtu.be/6eBHiUf7SF8>

When it came towards the end, the doctors, the palliative care team, the social worker, Lidia's father and I, we all sat and discussed what was probably going to happen. We decided to let Luke know just -- we didn't want him to have regrets later on in life that we did not include him in the conversations that we didn't let him know what was going on. He was 11 when Lidia died. So I think it was helpful for him to know. And I think he's gotten through it rather well.



END-OF-LIFE: WISHES

I asked, "So Lydia, what you think you would want if you did die?"

<https://youtu.be/ApGoVDWsh5s>

Lydia was getting ready for bed one night and said, mom, do you think if I died now, would god let me see myself as a teenager? And I said, yeah. I think he would. And that was the catalyst for our beginning to speak honestly about what may happen. And so since the door was open, I took the opportunity and I said, so Lidia, what do you think you would want if you did die. So would you want to be buried in Minnesota with your grandma, would you want to -- would you want me to cremate you and just keep you in the house and then you'd always be with me, or what would you want.

She was like, I think I want to be buried in the cemetery by my school which is the cemetery we had walked through, you know, unwittingly. And it just did -- it gave her a peace of mind where she wanted to be. And it's actually right across the harbor from her elementary school. So once that door was opened, we were able just to talk casually about death, I mean, not that a conversation about death is casual, but if a question came up or a thought, it was okay to talk about. We had crossed that line and we both now felt like it was okay to talk about.

And during those discussions, Lidia was able to tell me that she wanted a white coffin with bling. She had specifically said if she died, she wanted the Teddy bear that was at her school sitting in her seat when she was unable to go to school to come of the funeral and the little bear that looked just like that Teddy bear that she kept at home to remind her of her classmates, she wanted that buried with her. So in the end, when was all done and said, it was such a relief to know that her desires were met. In my moment of worst grief, I didn't have to make those hard, hard decisions because this little girl who is unable to chose what was happening to her body in life had made those choices for what happened to her body in death.

She was willing to go there with me.

<https://youtu.be/e-qFBgkx-8>

Paula: I'd say if she opened the doors such as with that question, then I was willing to sit down and ask the questions that I wanted answers to as well. And she was willing to go there with me. And sometimes even like at night, she'd want to read the Bible and that could sometimes help us to enter into the conversation like Corinthians 13:13, these whole faith in love, these things remain and the greatest of these is love. I mean, that was just a nice conversation of, listen, our love for each other is not going to change. Even if you are in heaven and I'm on Earth, we still have a future to hope for and that we both have to have faith for that. And it was a way of easing into, I guess, what was coming.

She was able to look at me and say, "Mom, I am dying."

https://youtu.be/ZQ5Q_6dczp4

Lydia: Maybe two days before she died, she was actually able just to look at me and say, mom, I am dying. And we were once again blessed to be able to have a conversation about that and just, you know, she wanted to know if we be okay.

And I was able to relate to her that, Lidia, you remember my mom died not that long ago, and we talked about how that grief process was. I'm like, Lidia, remember when mom died, some days I'd cry and I have hard days and I missed her terribly. But you and I, we were able to go on, we were able to still laugh, we are still able to have good days. And yes, I missed her. I missed her everyday and you missed her everyday, but we are okay. And I said that what it's going to be like when you go to heaven. I said, I will miss you so much, but I am still going to be able to live just like I was still able to live after my mom died. And I said now we know why mom died. She is going to be there on the other side to take care of you and you're going to be fine. I said, for you, it's going to seem like a minute before I am going to be there. For me it's going to seem a little longer, but we'll be together again and it's going to okay.

Those conversations ended up being my saving grace because then I had no regrets.

<https://youtu.be/sSzBvJeO3XY>

Paula: But even the days before that sometimes like she would sit on my lap and I couldn't help crying and I would cry. And she was like mother maid. She would pat me on the back and say, mom, it's okay. You can cry as much as you need to. And it was such a great thing to be able to comfort one another.

For her to comfort me, for me to comfort her, there wasn't anything left unsaid. You know, we are able to say, you know, I am sorry, I was -- sometimes impatient. I am sorry for everything I didn't do right as your mother. And she was able to say that she was sorry when she wasn't, you

know, the perfect child to. And we were just able to do all those things that you would want to do. Forgive each other, express your love.

So in the end having those conversations about death that seemed like that would be the scariest things to have in the world, those conversations end up being my saving grace. It ended up being the result of not having regrets. Those conversations let me know what Lidia needed, what Lidia wanted and it just has helped in the healing process in so many ways because there aren't those huge regrets. There aren't those big questions if would this be what she wanted.

Doctors should know that getting past the fear of it is the biggest step.

<https://youtu.be/I5QGUEiv91Q>

Paula: I think once you get pass that fear, those conversations can be a good thing. I think -- I did not feel like the doctors that we had were against having those conversations. I think that they were a little bit more pro-conversation and pro-openness just as I said earlier that they wanted us to be able to talk to our son openly and let him know what was going on so that he would not be later on coming back with regrets themselves of perhaps not saying goodbye, or not understanding what was happening, or really knowing that the end was near.

So I think they are prompting to show their openness to it. So I was happy that they were open like that and I think it was helpful. And I think other doctors should know that getting pass the fear of it is the biggest step. I feel like I have less fear in my life in general because of it. Once you face your hardest fears, you are not as afraid of new or different things.



END-OF-LIFE: OME VS HOSPITAL

I am grateful I took the risk of bringing her home because that is where she wanted to be when she died.

Paula: Her body was shutting down, you know, bit by bit. And she was happy to be home though. The first days she was, you know, still able to, like, get out of bed and go to bathroom and -- but it was little bit overwhelming. Hospice sending over this medicine, the just in case medicine, just in case she has oxygen starvation, you know, the doctors had told us, be ready with dark towels and dark sheets in case there is bleeding. Thank god, there was not bleeding.

There were a lot of like worse thing -- worse case scenario that we had prepared for that did not happen. In the end, her death was rather peaceful, and I am so grateful I took the risk of bringing her home because number one, that's where she wanted to be when she died. Number two, I think she was so much more comfortable just being in her own bed, just with her own things around.



WHEN THE TIME COMES

All of us spent time with her after her death.

Paula: When Lidia was dying -- well, the night before Lidia died, she was having a really hard time getting to sleep. She was having kind of difficult time breathing. So she probably didn't fall asleep until really 4:00 or 5:00 o'clock in the morning. And when I woke up at like 8:00, I could tell her breathing had really slowed down. Her hands were little bluish. You could tell that the oxygen wasn't going through as it should. I called Lidia's dad to let him know that I didn't think that she had long and he went to pick up Luke at school.

We had sent our son to school because it was -- it was just so hard. I mean, do you want to really just sit and wait for death. It seems so depressing. And so we figured let him have a good day at school until whatever happens. And if we know that something's happening, we will call. So when Luke's dad went to pick him up, for some reason they got behind a truck or something and they were delayed. So by the time they actually walked in the door, Lidia had passed away. But I think it was okay that he did not have to literally see her die. And all of us spent time with her after her death. Just each of us hugged her. I held her for quite a while and just we had our intimate goodbyes.



BEREAVEMENT

For me, not holding on to the details is helpful.

<https://youtu.be/Low-yZ1YQts>

Paula: I have not held on to a lot of the details. I know there are parents who -- they can tell you how many blood transfusions there were. They can tell you how many days they spent in the hospital. I find for me not holding on to the details is more helpful. So discussing them now, it's kind of like all the blur, but that blur is kind of what helps me through because I think if I were holding on to every little detail, I wouldn't be here right now speaking with you. I'd be at home in bed under the covers.

The funeral began the healing.

<https://youtu.be/GKqsbDDPTIQ>

Paula: I think the first few weeks, maybe even months, are the hardest, just adjusting to the fact that your child is no longer there. For us, I think the healing really kind of started with the funeral. We wrote in the obituary, anybody coming to the funeral please feel free to red. Red was Lidia's favorite color. And we want to honor that.

So you know, I think we tried to choose happier songs, maybe not. I mean, we didn't want it to be a depressing thing. I brought the Teddy bear like Lidia wanted. She had been given a recordable book when we are on her make a wish trip. So as soon as we got home, she recorded herself reading that book and that was like the last thing I did at the funeral like for the eulogy, I let Lidia's voice ring out reading her words of how much she -- the book was something I love you. It expressed love.

So it was her voice ending the eulogy with how much she loves you. And so it was a beautiful thing, and then each of her classmates at the burial put -- actually I think everybody at the burial put a rose on the coffin and then we had sort of a family party afterwards at our friend's house and the kids knowing that she left Katy Perry's firework song saying and danced to that song and let red balloons go in the air, environmentally friendly red balloons, by the way. And I just that -- you know, for her classmates, for some of those kids that this may have been their first experience with death, it didn't seem like this really, dark, ugly thing, but it was rather a celebration of life. And I think that was such a good way to start off the grieving process, you know, where we celebrated the life that was instead of making it a dark place.

It's like planting seeds in the garden, her life keeps growing.

<https://youtu.be/d5cBx5gaRFw>

Paula: I think it does shift through time in the beginning. You feel like you are never going to get through it. It's such a great loss. But you find a way to, I guess, use your circumstance to maybe extend their life which sounds little crazy, but just thinking like, the school wanted to make a little memorial garden. So I shared some of her artwork. Somebody -- the architectural, the landscape architect decided that one of her pieces would make an amazing sculpture. And so they've turned some of her artwork into a sculpture. And sharing her words in that memorial garden on the bench, we share Lidia said -- like maybe five days before death, she just felt like it was so important to say that, I hope I'm saying this right. I don't have it with me exactly, but she said, before cancer I used to judge people. If they looked different, talked different, walked different, I judged them. But after cancer, I don't do that anymore. Now I know what it's like walking, talking and looking different.

And so we shared that at the school on the bench hoping that other kids will read that and think twice before judging somebody else and maybe coming to that acknowledgement that the person I'm judging could someday be me. And so I feel like through this grieving process, anytime I can use Lidia's words, her art, her story, her love and put it out there in the world in some way, then it's a gain for Lidia. It's like planting seeds in the garden and her life keeps growing and changing and still adding to people's life. She may not physically be here, but her life still is extended here through those small things.

Try a group, there is something cathartic about grieving with other people.

<https://youtu.be/8qXWSp-2oZo>

Paula: I would just say if you do become part of a bereaved family, if you do lose your child, try a group. And even if the first group doesn't work, try another group because there's something so cathartic about grieving with other people, about knowing you are not the only one in that situation, knowing that other people are going through what you're going through, it makes such a big difference.

And sometimes, you know, other parents or friends or neighbors or family, they're going to say the wrong thing to you. They are going to make you angry, but somebody who has also lost a child, they are actually the people who are going to know what to say to you and kind of help you walk through it. It's a hard journey to walk alone and finding somebody who really understands and has kind of the same perspective, it can be so helpful.



TRANSFORMATION AND MEANING MAKING

Each small step moves you forward into finding that meaning for you.

<https://youtu.be/rcdrUcmIWgg>

Paula: It does change the way. I think I do live my life because I feel like someday I'm going to have to face her. And if I waste my life and if I don't do something with it, she is going to be made at me. She'd be like, I had nine years and you had how long. And what did you do with that time, really. So I just -- I can see her little hand on the head, going. So I feel like, yes, I have to take into consideration her life as I lived my life, like it just -- I have to do something with because otherwise it would be so sad.

If she didn't get the opportunity and I have the opportunity and I don't do with it, something that she would have had she had the opportunity, then I wasted my life. So I need to just keep moving forward. And I think for people who have lost their kids, I think everybody does want to find that meaning. I think being around other bereaved families and watching them do amazing things really helps because each time you just put one foot in front of the other. Each time you just keep moving forward, things happen. You know, whether you are the type of person you starts the foundation or runs a marathon to raise money or writes a book, or you know, shares your child's artwork, it doesn't have to be big. But each small step, I think, moves you forward into finding that meaning for you.