Robin Kanarek Video Selects

Lower Third:

Robin Bennett Kanarek, RN

Mother of David who had leukemia.
Palliative care advocate and author of [*Living Well with a Serious Illness*,](https://www.amazon.com/Living-Well-Serious-Illness-Palliative/dp/1421445980/ref%3Dsr_1_1?crid=2IU1YWNVIQWFW&keywords=living+well+with+a+serious+illness&qid=1678385324&s=books&sprefix=living+well+with+a+serious+illness%2Cstripbooks%2C90&sr=1-1)

|  |  |
| --- | --- |
| 1 | Title: *A mother and nurse’s personal journey to palliative care advocate.*<https://youtu.be/q26MublGuZE>Robin Bennett Kanarek, RN, mother of David who had leukemia, talks about her becoming an advocate for palliative care. "David had great medical care, but there's a whole other aspect of [psycho-social] care that he lacked and suffered from"I go by my full name, which is Robin and my maiden name, which is Bennett Kanarek, Robin Bennett Kanarek, I've been an RN for 45 years. I am the president of the Kanarek Family Foundation, which is a foundation my husband and I started in 2006 to promote palliative care for anyone with a serious illness, primarily focusing on educating healthcare professionals, that really is the goal because they'll disseminate all the information. And so that's what I -- how I identify myself. I really, as a nurse, I've always had a love hate relationship with nursing, it's a really tough occupation to be in, well, any occupation in healthcare is difficult right now. But it is -- nursing has always been a challenge, and from the time I graduated, there was always a nursing shortage, and I don't think it'll ever change. But I have to tell you, it's probably the best choice of a career that I chose. I am so grateful for my nursing background.I met a nursing professor at Fairfield University, which is where I had gone to nursing school, and I wanted to do something in David's memory, I wanted to educate nurses. But at that point, adolescent oncology was just started in the US where the UK was way ahead of us. And so this professor said, why don't you do -- why don’t you focus on palliative care? I think everything that you feel David was lacking, which is mostly psychosocial and spiritual, those were the areas where I just didn't feel David got the attention, they should have or us should have gotten, so that's why I started, when she told me this, I started saying, okay, this is what I'm going to read about, I'm going to learn about this. And it really was pivotal, because that's exactly what David needed. And when I saw that, I said, okay, this is the direction we're going to go. Prior to David's illness, I dealt with chronic illness, I dealt with diabetes, spinal cord injury, stroke, cardiac disease, I mean, that was what I did, because I really liked establishing rapport with the patient, and the two areas in healthcare I did not want to go in and I knew this very early on in my career was pediatrics and oncology, and look what life threw me. The two things I dreaded are what came to me. And so I figured, okay, then, I've got to take this, And I've got to make -- I've got to learn everything that there is to know, so I can take care of my son, and I wished he had all this provided to him, But it wasn't, he had great medical care, but there's a whole other aspect of care that he suffered from. |
| 2 | Title: *David’s reaction to his cancer at 10 when very different than his reaction when he relapsed at 14.*<https://youtu.be/edtGHq2j6Fg>The mother of a child diagnosed with leukemia describes how he reacted to the diagnosis at age 10 -- "OK, how are you going to treat it? Mom"; vs "Why me? What did I do?" when he relapsed at age 14. He learned that life is not fair. She also discusses how there is a lack of religious leaders who know how to support adolescents going through this. "It is a very special conversation and it needs to be practiced alot."David’s story, he was 10 when he was diagnosed. And his reaction at 10 was very different than his reaction when he relapsed at 14. At 10, David, you know, was still a young boy, and, you know, his idea of fun was bike riding and playing with his dog and his neighbors, all the typical things a 10 year old does. And so when he had his severe hip pain, and joint pain, I really thought he was making it up, because David didn't like going to school, and he just wanted to stay home and watch TV, and so I didn't believe him, I really thought he was making it up. And then eventually after a couple of weeks, we found out that it was leukemia and David's reaction when we told him he had leukemia, he didn't know what leukemia was, he didn't know what cancer was. So his reaction was okay, I have cancer, how you going to treat it? And he just thought he was going to get better. And then, when he was 14, his experience was he had -- his reaction was why me? Why is this happening to me? What did I do to deserve this? And I had, of course, you have no answer for that. And he was very aware of what the chemo was, he was aware of the pills he was going to have to take, and how he was going to feel, he knew everything. And so to him, it was just torture the second time around. And I’d learned -- so those were totally different reactions as a 10 year old he reacted like as long as he looked at me and he said, am I going to be okay? And I said, yes, then he believed me. But at 14, he had the maturity to realize that, okay, you can't really protect me from this. What's going to happen? And he was scared. He was terrified. He didn't tell us that. **Robin:**  There's no answer, there's no answer. You know, I just said, it's not something you did, this is like the oncologist says it S, blank, blank T happens, and that's -- I think that's the realization that, you know, life is not fair, and it's one of those very tough life lessons, and my husband, and I wish we could have -- it would have been us and not him, he didn't do anything to deserve this.Honestly, I don't think there are a lot of rabbis or priests who know how to have this type of conversation. I do spiritual support at a local hospital, and our rabbi at the hospital is trained in palliative care, so she knows how to have the discussions, but the priests don't, they aren't trained in this. I mean, it's a very specialized conversation, and it has to be practiced a lot. |
| 3 | Title: *Bereaved parents fund nursing education to promote serious illness conversations: the power of words and allowing silence.*<https://youtu.be/dP2hU8FKuEQ>Mother and Nurse Robin Kanarek describes the program her family foundation funds at Memorial Sloan Kettering to train nurse practitioners (using actors and simulations) in serious illness conversations. "The words they chose have a lasting impact on the parents. . . Silence is perhaps the most important thing because then the parents blurt something out."our family foundation in 2010 provided a grant for nurse practitioners at Memorial Sloan Kettering to educate them on these difficult conversations, because it was the doctors who were trained in it, and Sloan Kettering has a program called Calm Skill, which is basically a simulation, a live simulation using professional actors, showing them presenting very difficult scenarios, and seeing how the doctors but in this case, the nurse practitioners will take the conversation. And I have to be honest, many times the doctors will give the bad diagnosis. And, you know, the patients are kind of uncomfortable with the doctor and don't know how much to ask, and the doctor will leave and then it's the nurse will come in. And the patient and the family will say, oh, I forgot to ask this question. Can you answer this for me? And so it will be the nurse or the nurse practitioner will pick up the pieces. So that's to me why nurse practitioners and nurses have to be educated. And I have to be honest, the nurses who I watched because I sat in the room, and it was videotape. These nurses knew how to do it, they just needed validation that they were doing it correctly. But I mean one of the scenarios where the parents were being told that their child, there's nothing else that they could do for them, and that right now it's just comfort measures and the parents, and it's just amazing the actors who were playing the role of the parents were, I have to tell you, it was the most convincing acting that I have ever seen, I've never seen any -- I mean, I was just shocked, my mouth dropped, and I couldn't believe and, you know, the actors were really emotional, and the nurses kept calm, you could see them pausing and trying to gather their thoughts. And the choice of words that they make will have a lasting impact on the parents. So that's why those words that you choose, and never assuming anything, and just allowing and silence is probably the most important cue for me, because it's through silence that will get the parent to open up and to share. And so don't force the conversation, just allow silence and something will come out, because I found that happen to me, when someone allowed silence, you get so uncomfortable with the silence that as the parent you just blurt something out, and those blurts usually are important cues as to what's going on. |
| 4 | Title: *Pediatric cancer: My teenage son was going through spiritual distress; he had questions about his mortality. Palliative care helps with that.*<https://youtu.be/sGzBr2LuG80>Robin Kanarek, mother of David who had leukemia, talks about the acute spiritual distress that her14-year old son experienced during the isolation required following the stem cell transplant. "He was questioning what was going on; his mortality" She references the work of Elizabeth Kubler Ross who recognized that teenagers won't discuss such things with their parents. She stresses that adults don't properly acknowledge the spiritual lives of adolescents living with illness. Palliative care helps with that.So David had to be irradiated, which meant that his whole immune system had to be knocked out, and they had to introduce a new immune system, which was his sister. And so David was immuno compromised, I mean, he had no immune system at that point. And so afterwards, you have to go into strict isolation, because your body cannot fight anything until the new stem cells take harvest in your body and they multiply and grow. And so David was in strict isolation in Sloan. And the first week he's fine, not feeling well, but he's okay, but the second week, I saw a profound change in his personality, I mean, David was a very easy going, happy go lucky child, always with a joke. And all of a sudden, I saw massive change in his behavior, he was confrontational, belligerent. He was confrontational not only with us, but also the healthcare providers, and this was not David and I kept asking all the nurses and the doctors, I said, what is going on here, and they all said the same thing, they said, we have seen this before with transplant, not only cancer transplant, but lung transplant, heart, kidney transplant, we see this with transplant -- children who wonder go transplant, and that was all they could say, they never took it a step further. So it wasn't -- so I saw that there was really a problem here with David. He wasn't going through pain, physical pain, he was going through spiritual distress, where he was questioning what was going on. And I had a feeling from my early years in nursing, and really being a profound fan of Dr. Elisabeth Kübler-Ross, who was the doctor who came up with the stages of grief. I really had a sense that David had questions about his mortality, but he did not bring this up to me, and from her writings, she wrote that normally, teenagers will not talk about this with their parents because they don't want to pain their parents anymore. So I didn't bring this up, but I had a feeling that this was the problem. So I asked a child psychiatrist to go in, and there was only one child psychiatrist in the institution, and he just wanted to talk about David's relationship with me. And David, after the first go round with him, and the doctor came back to have another round with him, David said, no, I don't want to talk to you, this is not the issue, I don't have a problem with my mom, I have a problem with what I'm going through, and so we fired the doctor. So finally, what happened was, I asked David's favorite doctor who came in to visit him. and I said, David has questions about his own mortality, I'm asking you to go in to talk to him. And the doctor had this look like a deer in front of headlights, and it was very obvious he was not comfortable with this. And I said, if you don't have the conversation, no one discuss this with him, I said you have to go. And I didn't give him a choice. He went into the room, three hours later, he came out of the room, didn't tell me what was discussed, but he said your son had a lot of questions, he had a lot of philosophical questions. And so -- and he walked away, he was exhausted, I mean, you could see the sweat pouring down his face. So my husband and I looked at each other, and we thought, how are we going to have follow up on this discussion, and we walked into the room, and lo and behold, David was smiling, couldn't believe it, could not believe it. He was just like this burden had been lifted from his shoulders, and he was ready to go forward, and he was back to his old self. So I have to tell you that was incredible to me. But it wasn't until 20 years later, when I -- we had Dr. Christina Puchalski from George Washington University, who does palliative care at George Washington University and also responsible for spiritual cares, educating healthcare providers on spiritual distress. She came to the Fairfield University School of Nursing to talk to health care providers about spiritual distress. And they're asking her the symptoms, what are the symptoms that adults display? She said, anger, belligerence, there'll be confrontational, they're going to have sleeping problems, they're going to be very depressed. And at the end of the presentation, I stood up, and I said, I just want you to know what you just described, my 15 year old son went through, that's exactly what he went through, went through. And I said, but no one had an answer for us, and you're giving me the answer now that David was undergoing spiritual distress.that's one thing that Kübler-Ross talks about in her book children who are dying. And it was very, very powerful how children are innately very spiritual, and I think as adults we teach them to suppress it. I think if had this discussion started much earlier, and that's the true art of palliative care that you can be getting curative treatment, and you're just supporting the whole family through this trajectory, you don't know what's going to happen, but if you know you're going to be supported. So if something negative happens, something terrible happens, where you get that bad news, you're going to have a team in place that's going to support you, and that's what the beauty of palliative care, that it can be started so early. So none of this is like at the last moment, because that's the one thing I really resent when people bring this up to you, when it's so late in the illness, this should have been brought up much earlier.I know the five wishes, the document, the five wishes that to me is such a gift, because you're planting the seed for the conversation, and this is a conversation that has to be made in a very relaxed atmosphere, where you're not thinking about, okay, what are you going to do in case an emergency, but it just opens the door, and that's what you need to have done. And look at how happy he was after he emburdened all that, it's changed him, it just changed him. |
| 5 | Title: *Pediatric cancer: making the decision to stop treatment is the hardest decision a parent will make in their whole life.*<https://youtu.be/-ksUugzf-Ik>Robin Kanarek, mother of an adolescent who had leukemia, talks about parents' having awareness that their child could not survive the cancer and that doctors don't speak of all the potential outcomes. "You as a parent have to ask the tough questions." She tells the story of a doctor who pushed back aggressively against parents who wanted to transition their son's care, post multiple relapses, to hospice.**Robin:**  So I think as a parent, the most important thing, if I can convey anything is how you have to be your child's advocate, and you cannot expect that the doctors are going to bring up everything to you, you have to just put it out there, and if you have a difficult question, basically asking, what are the chances for survival, I mean, you need to know that, and you need to -- because you need to mentally prepare, and my husband and I we’re always aware that David could go. And we were so grateful for the time that we did have with him, and we did have a good year with him. But the fact is, is that doctors don't always, I mean, like even when you go in for surgery, they don't tell you all the complications that can go on, they just tell you the basics and they skirt over, but you have to as the parent, ask the tough questions. **Robin:**  It's tough because you don't know how you think the doctor is going to yell at you. You think the doctor is going to look at you like, what makes you say that? You don't know how it's going to be perceived. I'm sure there are doctors who [00:59:00:08] oh, you hear stories, I knew of a family who -- a grandfather whose grandson relapsed with leukemia, the child was a year and a half and had relapsed five times. And the man worked for a big insurance company, and he had read one of my articles and it turned out his father who was the grandfather knew us. And the grandfather called me up and he said, I want your opinion on this. He said, my grandson has relapsed five times, he's a year and a half, my son decided that they wanted to do hospice care and change this over, the doctor wanted to do a stem cell transplant, I looked at all the numbers, and the numbers did not look good, he didn't have one patient who survived, the doctor did not tell the father that. And the long term results of having a child be immunosuppressed at 15-18 months, and the doctor looked at him saying, I will call social services on you.**Blyth:**  Wait, if you don't move forward with the transplant?**Robin:**  Yes.**Blyth:**  So then what happened?**Robin:**  So the man said, okay, if you're going to call social services on me, because I think we've done all that we can do for my son, then I'm going to notify the insurance company, that you are -- want to do a surgery, that hasn't been proven to work. And I have to tell you, I mean, that's an example of where as a parent, you made the most difficult decision there is in life.Any parent who takes it to the next step and says, okay, this is where we want to stop treatment, it has to be honored and the health care provider needs to know that that parent -- those parents had taken a lot of time to think about this, it's the hardest decision you'll make in your whole life. |
| 6 | Title: *Every parent wants their child to live no matter what but at what cost? It takes weeks, months to come to terms with this.*<https://youtu.be/ViiqwlIoGtM>The mother of a teenage boy with leukemia discusses her and her husband's respective journeys to understanding that their son would not survive his cancer. She stresses the importance of the interdisciplinary team talking to the parents. "As long as the parent is well equipped with this information, then they can make a somewhat positive decision . . . . It's a process, it doesn't happen overnight, it takes days, if not weeks or months, to come to terms with this."I think every parent wants their child to live no matter what, but at what cost. I think being a nurse I have seen, and I have helped both my parents die a very comfortable death where I wanted -- that there was no more treatment that was provided, but they did want to have -- they wanted music to be played, they wanted a comfortable, relaxing environment, they wanted their loved ones by their bed and providing them the input that they wanted to hear. So both my parents died very peacefully. And I have to tell you that brings tremendous solace to me. But as a parent, who has a young child, you have to be really well educated as to -- and that's where you really are depending on the team, and it's not just one person, it's a whole team that needs to talk to you and sit with you, and spell out what it can -- what it means from a physical therapy standpoint, from an occupational therapy standpoint, from medication standpoint, from a psychosocial standpoint, these are all the different areas that have to be highlighted. And as long as the parent is well equipped with this information, then they can make a somewhat positive decision, but it's tough, it's the hardest, as I keep saying it, it's the hardest decision you'll make, and knowing when to stop treatment. And I think you have to look at the child, how are they responding to the treatment. Are they -- does the child seem hopeful? Does the child seem like for example, with this organization in London, Teenage Cancer Trust, I dealt with a nurse who counseled teenagers who were dying, they had a BBC interview with this nurse with these teenagers who relapsed five times. And finally the child -- the teenager says, I don't want to go through treatment again, I've had enough, I don't want to end my life like this. And I think that is the true art is, for someone to be able to listen to what they're saying and to honor it, the parents in those situations did not want to hear that, they wanted to hear that there was every chance possible, and we should keep plugging along, but these teenagers had enough. And they felt like they were -- they just couldn't do it anymore, they didn't have it in them, it's tough on the body. I mean, when my son relapsed, I mean he couldn't walk at that point, he was still very, very, very weak from the chemotherapy. So those are all this instances that have to be brought up to the parents.I think it's just knowing that it's a process, it doesn't happen overnight, it takes days, if not weeks or months, to come to terms with this, this is not something that you have to make a decision right away, you should be thinking about this and really discussing it with the doctor, the nurse practitioner, the psychologist, the chaplain, these are all discussions, not just one person, so that's the one thing. |
| 7 | Title: Writing the book *Living Well with a Serious Illness*<https://youtu.be/mENpbLRIKDw>Robin Kanarek, a palliative care advocate and mother of David who had leukemia, explains that she wrote the book to educate PATIENTS about the value of palliative care.**Robin:**  I wrote the book as a result of several years of educating health care providers about what palliative care is. I was going to conferences, I was speaking at nursing schools, and then all of a sudden, I realized, okay, healthcare providers are learning this, but who's teaching the patients. And so I decided to do a literature review, which is one of the things you learn in nursing research as to what type of educational material was out there for the patient, and there was nothing. I mean, you would find a doctor writing a book about the cancer journey. And he or she might highlight palliative care, but it's like in a chapter or maybe a paragraph, there wasn't a whole book. And the one thing I did when I was going through my healing process is whenever I found an article that really touched me, I saved it, and by the end of 15 years, I had a huge notebook, and through that I had a book. And just integrated my stories, our personal stories with what research is showing, and so the book is written for the lay consumer, someone who is not in health care at all. So I wrote it on a very basic level that anyone can understand, so I'm hoping that doctors and nurses will promote this for their patients. But also, my secondary gain is I'm hoping that nurses and doctors, anyone who goes into healthcare needs to know what palliative care is, can get a -- it's a quick read, it's an easy read. And so that was the reason why I wrote the book. Because there's so many people with serious illnesses and multiple chronic conditions and children who are going through a difficult diagnosis. But you need to have the basic conversations and this outlines it. |