Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Welcome to Nightintales. This podcast was created during the International Year of the Nurse and Nurse Midwife, and what a year that was. This podcast is dedicated to telling stories of nurses from across our profession. Our goal is to introduce you to the seemingly infinite possibilities in nursing, and encourage you to find your true passion within this work. I'm your host, Jessica Spruit, and I'm so glad you're here.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Hi, and thank you for joining us for another episode of Nightintales. I'm very glad you guys are here today. This is a topic that we're going to talk about. That's near and dear to my heart, and we're featuring a really special guest. Who has really embraced the role of a nurse in a palliative care role, and has so much insight and wisdom to offer us.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

And so I'd like to welcome Maureen Giacomazza. She has served as a clinical nurse consultant at Michigan Medicine, at CS Mott Children's Hospital, and worked with the inpatient Stepping Stones Pediatric Palliative Care team there. And Maureen also has been prepared, she earned a master's degree in bioethics, and just has a really unique perspective. And I think that there are some really good lessons in this episode for everyone who's going to care for families in times of distress and also through times of triumph. So Maureen, thank you so much for joining us today.

Maureen Giacomazza, MA, RN:

Oh, thank you so much for inviting me, Jessica. This is a real honor and privilege to be able to have this conversation with you and with your students.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Well, as someone who I've learned so much from, I'm really excited for you to share your insight with the listeners of this podcast as well. So thank you.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

I was hoping Maureen, we could get started just by briefly telling us a little bit, please, about what made you want to go into nursing and where you started in nursing. So how did we get to the point that we are at? And then we'll talk a lot about what your role has been and your work in palliative care.

Maureen Giacomazza, MA, RN:

Sure. It's always a good place to start at the beginning. Now that I'm a grown adult, I can look back with some perspective and think about how fortunate I was to kind of always know what I wanted to do. I was four years old when I wanted to be a pediatric nurse. And that was inspired by, actually, being a hospitalized child. Nothing serious, thank goodness, but I was in the hospital, and that was back in the days when they kept you probably for a lot longer than they would nowadays. So I was in the hospital for a couple of weeks, and it's interesting to me there was a nurse that actually wasn't so kind to me, that was back in the days when parents could only come a couple of hours. My mother would come in the morning for a couple of hours and then my parents were allowed to come back at night.

Maureen Giacomazza, MA, RN:

And naturally, when they left, there was lots of tears on my part. It's very scary for a child to be there all alone. And this nurse was just not so nice to me about that, nothing what I thought should have been something comforting. And right then, I thought to myself, you know what, when I grow up, I'm going to be a nurse and take care of children, but I'm going to be really nice to them.

Maureen Giacomazza, MA, RN:

And I shared that story with someone one day and they said, "Oh, so right from the beginning, you wanted to be a change agent." And I thought to myself, wow, I hadn't really recognized that or thought about that, but I guess you're right. I was really inspired by that, unfortunately, not necessarily inspired by a good nurse, but rather somebody that I thought didn't do the job so well. But I thought that's it, I'm going to make a change. I make a difference and make things better for other children. So that's how I got started in this profession.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Wow. I love that, too, because really we think of like change agents and disruptors, and those things now in such a favorable light, we recognize that's what nursing needs. And who knew that at four years old, that was already your vision.

Maureen Giacomazza, MA, RN:

Yeah. Right. Right.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

You have fulfilled it though Maureen, I'm anxious to talk more about that. So you went to nursing school, did you come out the nicest pediatric nurse, the day that you graduated or how did that work for you?

Maureen Giacomazza, MA, RN:

I think, again, because I knew in my heart that that's what I wanted to do, even though I loved so many of my other clinicals, it's definitely one of those where when you're going through your OB clinical and I think, oh, maybe I really want to do this, and that I liked the psych clinical. And I thought, oh, maybe I actually like to do this. But in my heart of hearts, I went back to my original love. And when I did my pediatric rotation, I did it on the cardiology unit at Mott Children's Hospital. And I really liked the patient population. I loved learning about the congenital heart defects. And so I just went up to the nurse manager's door and knocked on her door, introduced myself, and asked her if she would hire me for the summer.

Maureen Giacomazza, MA, RN:

And much to my delight and surprise, she said that she would be interviewing people for the summer to help out as a nursing assistant. And I got the job, and stay there as a new grad. Always knowing though that I really wanted to work in critical care. But I think as a new grad, I was just a little too timid for that environment right off the start. Also, at Mott, they simply didn't hire new grads in the critical care unit, at that point. So I knew I had to get my feet wet on a general care unit. And I really, again, liked that congenital heart population. So I worked there for a couple years, until I felt really ready. And then from there moved into critical care where I remained for over 20 years.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Wow. So you went to critical care, having some background in pediatrics, having a background with a subpopulation of patients, what was the most challenging part of being a pediatric critical care nurse? Because I imagine that some kids get better and some don't, some are there for a long time and some are there for a short period of time. What was the most challenging part of that for you?

Maureen Giacomazza, MA, RN:

So the most challenging part of that for me was not the skills, I thought it would be. I remember, let's say for example, when I was on that congenital heart stepped on unit, if I had a patient who deteriorated and I sent them into the ICU, I remember just kind of being in awe, watching those ICU nurses swarm around that bed and they knew what to do. And I was just amazed. And, again, that's when I thought, wow, I want to be like them. I want to do that. And yet that wasn't the really big challenge. You learn those skills. You learn how to admit a motor vehicle trauma that you have to take the CT scan and they're on inotropes. And they're all of these things are going on.

Maureen Giacomazza, MA, RN:

The thing that I think I felt the most unprepared for and what was my biggest challenge that really led me to the rest of my career was, when people weren't talking about the big elephant in the room. It was when the patient was critically ill and the chance of recovery or any meaningful recovery looked very slim. And the way hospitals work, we all know that you have an attending physician who comes on for a week, maybe two weeks, they kind of put a plan in place, and we all kind of start going this road and then the next attending comes on. And maybe things change course a little bit or things don't unfold perhaps as I had hoped.

Maureen Giacomazza, MA, RN:

And I think that that was the biggest challenge for me was, recognizing that the elephant was in the room. Nobody was talking to the parents and really preparing them for the fact that this child was likely to die. And I really struggled with that. How do I answer the parents when they ask me, "Gee, Maureen, what do you think?" Do I answer them honestly? Is it my place to talk to them about that? How do we prepare them best?

Maureen Giacomazza, MA, RN:

Those were the challenges for me. And it was really more of the ethical dilemmas of wanting to do the right thing for this patient, but were we really doing the right thing by continuing this aggressive care with a poor likelihood of any good outcome? And that's what made me kind of decide to study bioethics. I thought at least it would help prepare me for how to have those conversations better.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Sure. Oh, I think that's such an important point, because as nurses, we often find ourselves, we are the most consistent at the bedside, we spend the most time in the room with patients and their families. We're also there, especially, I've always thought about night shift nurses who are there when the medical team go home, when the social worker's not there anymore, Child Life has left for the day. All of those distractions, all of those other supports and comforts around you are gone, and it's the family and the nurse. We're the ones that see all of that, really 24 hours a day.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

It's a such a unique privilege, I think, but also challenge in nursing that you have the most consistent and constant interaction with families. So do you mind telling us a little bit about your pursuit of more bioethics knowledge and a degree in bioethics? And how that supported your role as an ICU nurse?

Maureen Giacomazza, MA, RN:

Yeah, sure. So I had the wonderful opportunity to go and work overseas. I think that was... Well, again, when I was young, I didn't know what a bucket list was, and yet I always kind of had these things in my mind of things I wanted to do as a child. And so, one of them was not only to become a nurse, but to also live overseas. And a few years after I worked in the ICU, again, kind of wanting skills, my own ICU skills built up before I kind of make the next challenge or the next leap. So after I had worked in the ICU for, I think it was two years, I then applied for a job in the cardiac intensive care unit at the Hospital for Sick Children in London, more affectionately known as Great Ormond Street Hospital.

Maureen Giacomazza, MA, RN:

And while I was there, I had mentioned to my nurse colleagues that I was really interested in the field of bioethics, and on various occasions back home in the United States, I was starting to apply to various programs. Loyola has a wonderful program in bioethics as does Georgetown University. So I was starting to talk to people here in the United States, and one of my colleagues in London said, "Well, King's college here in London also has a program in bioethics."

Maureen Giacomazza, MA, RN:

So I took a look at that program and actually that one really just resonated with me more, because it's actually offered through the law school. So it's the Center for Medical Law and Ethics, and you spent half of the time studying philosophy and bioethics, and the other half of the time studying medical law in the law school. And I just really liked that program, because, again, kind of wanting to be a change agent, I just didn't know what was the best way to pursue making some changes related to end of life care for patients. Is it really going to be through ethics committees in a hospital? Or should I become a lawyer and perhaps try to back some kind of legislation? I was just really unsure of how to make a significant change, but I knew that care for dying children needed help.

Maureen Giacomazza, MA, RN:

And it was time for people to talk about the pink elephant in the room and think about care of the dying differently. I believed, even then, that there was something that could be defined as a good death for people. And just undergoing more and more and more aggressive care in an ICU setting is not what most of us think of when we think of a good death. You ask any American, "How do you want to die?" And most people will say, "I want to die in my home, surrounded by the love of my family or good friends." They don't say, "Oh, I really want to die in an ICU setting with lines and tubes and not being able to talk." That's not what they say.

Maureen Giacomazza, MA, RN:

So really wanting to make some kind of change, I was just unsure of how it was best for me to bring about that change. But I thought that that was a really good place to start. And so I spent two years at the Center for Medical Law and Ethics in London then studying bioethics.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Gosh, that's such a valuable compliment to the nursing education that you'd already received and your experience in nursing. I can't imagine how that has translated to your years doing the work that you've most recently done.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

So you started to talk about being a change agent and recognizing that perhaps the way that situations were playing out in the hospital, didn't align with the way that families or children might imagine them or might hope for them. So can you tell us a little bit about, there's a couple of things here, Maureen, so whatever way you think this would more naturally flow. But I'm thinking about what it means to have a palliative care team, the difference between palliative care and hospice, but also what it looked like for you to respond to you identified that something wasn't right. You had this recognition that the care we were providing, didn't align with perhaps the goals of patients and families. And so how did you solve that problem? Or how did you go about being part of the solution, I should say?

Maureen Giacomazza, MA, RN:

I think, in order to make a change, you have to just really just see where your ideas take you and continue to follow your heart, but really be open to and acknowledge that you're going to have a lot of roadblocks and stumbling things along the way. But when you know in your heart that, perhaps, you have an idea, or maybe you don't even know what the idea is, but what you need to do is just seek out like-minded colleagues and kind of band together and just see where things take you.

Maureen Giacomazza, MA, RN:

So again, I studied bioethics and I moved back to the United States, and immediately join the ethics committees at Mott. Surely, just sitting on the ethics committee will improve things, right? And yet I was, again, in actual fact, I was quite disappointed.

Maureen Giacomazza, MA, RN:

Our ethics committees, these days are much more proactive, but at the time, this was in the early '90s, they were a very reactive group. So perhaps a team was struggling with a particular case, and they were at an impasse. Maybe the family wanted to do one thing and the team wanted to do another or to teams were competing and fighting. And then it would go to the ethics committee to try to seek some kind of resolution or what is the best path forward. But it meant people had to call us, it was reactive. And I just wanted to be much more proactive, can't we start these discussions really before they reach this climax of conflict. I hate conflict, and so I try to avoid conflict. And I hated to see them always get to this point and escalate to that kind of critical point.

Maureen Giacomazza, MA, RN:

So I was a little disappointed at first in joining the ethics committees, and thinking, I was... it just didn't feel like I was making a good change for end of life care. And yet I did a little study and looked at the cases that came before the ethics committee, and about 80% of them had to deal with end of life. So I knew it was a big thing, and people are really struggling with how to provide good end of life care, but waiting until there's a big conflict and then trying to resolve things was just, to me, not proactive and not. So again, I kind of thought, maybe I need to do this through the law somehow.

Maureen Giacomazza, MA, RN:

And I just happened to be at a nursing conference. Well, actually it was a conference through the American Society of Law, Medicine, and Ethics. And just standing there at a coffee break, having a conversation with a lawyer and he was asking me what I do, where do I work? And I shared with him that I was a long time ICU nurse. "I've been an ICU nurse for over 20 years. And yet we still don't talk about the elephant in the room. I want to change way people die in America. I want to make a difference, especially for dying children, and more children should be going home and in hospice care and dying a better death." And I told him, "I've applied to law schools. That's it, I'm getting out of nursing, and I'm going to go to law school and somehow I'm going to make this big difference."

Maureen Giacomazza, MA, RN:

And he kind of shook his head and looked at me, and he said, "If you really want to make a difference in the lives of your patients, don't go to law school." He said, "You need to stay in the hospital and you need to make a change there for the better. That's where things are going to change." And I was like, wow. I mean, it just really hit me when he said that. Here, I had my applications in to different law schools and I had taken the LSATs, and worked hard. But thought, you know what he's right. I probably am not going to be able to kind of legislate these changes or cases like the Karen Ann Quinlan or Nancy Cruzan Case. Those are few and far between, and I could have far more impact just being a nurse.

Maureen Giacomazza, MA, RN:

So I went back to my ICU unit and just really started to have much more open and honest discussion with people about this. And somebody said, "Well, gee, have you met so and so? They're thinking of something like that too." "And have you met this person?" And just gathering around like minds was so helpful. And together we really worked hard to bring about the change that we have today in the formation of both the adults and pediatric palliative care program.

Maureen Giacomazza, MA, RN:

So it's nothing you can... certainly, I want people to believe that they can make a change as one, but making a change as two, three, four, five, and getting a team together is even stronger and even better. So seeking out those like-minded people can really make a huge difference.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Sure. So what I'm here, Maureen, and what I love about this is, you recognized that need, you are struggling as a nurse, kind of torn in delivering care with an elephant in the room. I think that probably many nurses can relate to that. I think that in a variety of situations, maybe it's not the exact same situation as what you were facing, but I think a lot of us can struggle in nursing with, you're asked to do something day in and day out, but there's something much bigger that you're really struggling with. And I'm curious, how you would advise newer or aspiring nurses to feel more empowered or to try to be part of that solution like you were? Other than, you get a bigger team together, find like-minded people to support you, it sounds like perseverance was a big piece of that.

Maureen Giacomazza, MA, RN:

Yeah. I mean, perseverance definitely was. Yeah, I'm good at being a squeaky wheel. But yeah, I think, at first I certainly always felt empowered as an ICU nurse to speak up. And sometimes I would get some recognition, certainly, from perhaps the medical director of the team who would say, "Gee, I know what you mean. I'm struggling with that too." And at least I always felt very empowered to like call a team meeting. It doesn't even have to be a family meeting yet, but just getting your team in the same room and saying, "Gee, I'm really struggling with this. Are you feeling this too?" Can be so helpful to just be able to sit down and talk about a case.

Maureen Giacomazza, MA, RN:

I would recommend as a nurse that you reach out to the ethics committee, they are there to support you and there to help you, as is your team social worker and your spiritual care department. I would say, if you are struggling with the pink elephant in the room, so are others. And just being able to acknowledge that and seek out your nurse manager, your colleagues, again, using all the resources that are available to you, like the ethics committee, spiritual care, social work, really just trying to pull people together can make a huge difference.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Sure. Oh, I think that's helpful advice. And I hope that those of you listening will keep that in mind. You're often not alone, you're likely not alone, and you should feel as though you can speak up and be an advocate. And sometimes being an advocate, I think we talk a lot about, as a nurse, being a patient advocate, but I think also advocating for our own practice and what we know to be what is right and ethical is also important.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

So can you tell us, Maureen, please, tell us about this palliative care team and how this team was developed? And more importantly, I think, what services are offered by the palliative care team that you worked with? And what kinds of support you're able to offer families and teams within the hospital?

Maureen Giacomazza, MA, RN:

Sure. So our vision of a palliative care program at Mott was really to create a program that would be able to support the child throughout their illness. And that could even be from the time of diagnosis to either a cure, it doesn't have to end in death. So any child with, the words that we used is, a serious illness. At the beginning, oftentimes we talked about a life threatening illness or a life limiting illness. What we've learned from families, and it's important to gather their perspectives and their insights, and families said, "We don't want to hear that. Stop calling it life limiting." It's very threatening to them.

Maureen Giacomazza, MA, RN:

And instead we use the term, "It's a serious illness, we hope for a cure, for sure," but we're there to support and guide them throughout the trajectory. And I think right from the beginning of our program... And this was not something that was created overnight too, Jessica, I would share with your students that again, kind of the perseverance and the patience to maybe bring about a change, whether big or small.

Maureen Giacomazza, MA, RN:

Now, this was a big change, but then there's small changes that you can implement much quicker and on a daily basis. But this was certainly a big change to come up with a new program, a new service that wasn't previously available for the hospital, and it did not happen overnight. It took the better part of six years of hard work, going back to administration over and over and over again, presenting new data, doing more research, benchmarking with other hospitals that have that. If you have a great idea, find out if another hospital has that program or what they're already doing, because hospitals benchmark against other hospitals, and we compete and they don't want to hear that another hospital has a service that maybe we don't. So sometimes that can be your in, is just the competitive nature as well.

Maureen Giacomazza, MA, RN:

And so when we did finally, after, again, six long years of working on a business plan, and finally getting our proposal to be approved, we started out with just an inpatient consult service. So with that, we got consults from all the different medical specialties. Pediatric surgery was one of our big services that called us for help initially on, obviously, oncology, but we have since expanded to every specialty in the hospital. We see a lot of kids and receive a lot of consults from neurology, from neonatology, from cardiology. I can't think of a specialty that we don't provide consultation to.

Maureen Giacomazza, MA, RN:

And the idea was really to provide palliative care support to those patients of families. Sometimes there's not a decision to be made right now, but it's just getting to know them, getting to know their story, getting to know their hopes, and what their worries are. So those are some like initial questions we always ask families. What are you hoping for? What are you worried about? And just telling them that we're going to walk the road with them, in whichever outcome occurs. Again, and we all hope for the cure. We hope for the best, but we'll be there for them as well, if those hopes don't pan out.

Maureen Giacomazza, MA, RN:

And, really, while we were approved to be an inpatient consultation service, I would say, about 30% of our workload, right from the beginning was outpatient consults. People calling us saying, "Can you come to our clinic? We have this family and they really need help today and right now." And about 30% of our workload was outpatient. We now have an outpatient clinic as well. And now we've expanded to the partners program, where we have an outpatient provider service where nurse practitioners go into the home. And that has made a huge difference to families, in not needing to return to the hospital when there's a crisis at home or not needing to go to the emergency department to get an issue sorted out. We can send an NP into the home instead to do an assessment, who has a relationship with that family and that decreased the need for ED visits and rehospitalizations.

Maureen Giacomazza, MA, RN:

So the program has really, greatly expanded beyond the initial thought that we had of just being an inpatient consultation service. We do a lot of outpatient work, and I think that that's where conversations really should happen. It's much better and nicer for families to have those conversations in the comfort of their own home and to think and contemplate the what ifs, to contemplate what would we want done the next time Johnny might have to go to the ICU? Do we even want another ICU admission? They feel much freer to have those conversations in the comfort of their own home than when you hit the doors of the Ed.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Right. So when I think of the reasons that team or nurses might seek out a palliative care consultation, so maybe you're not the nurse on palliative care, but you're caring for a family where there's a lot of distress or something. So I think Maureen started to clarify, this is not always going to end in end of life. This is not like hospice, where there's a requirement of an expectation that the patient may not survive for greater than six months or something like that.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Palliative care, I think, when thinking about when would be a good time to engage palliative care, I think, like you said, Maureen, certainly with patients who have serious illnesses, perhaps even at the time of diagnosis. I think about some of the patients who prenatally even are diagnosed with a congenital heart defect, where there may be a long road ahead or some important decisions to make, or perhaps a tumor that we know can be really problematic in children.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

And then I think also, when families are faced with difficult decisions and an added layer of support would be helpful for them. And then, also, I think as a nurse, we often are also aware of symptom burden, when patients have refractory nausea and vomiting, or when they're experiencing a lot of pain. And the primary team is having a really difficult time, perhaps getting their pain under control. It seems that palliative care often and has a whole toolbox of ideas that haven't yet been explored by primary team. They've always got something else up their sleeve.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

And so I was just thinking, as a nurse, who maybe isn't on a palliative care team, but what could a palliative care team offer in support? I think those are some of the reasons where we would engage palliative of care. Are there others that you think listeners should know about or should kind of have palliative on their radar?

Maureen Giacomazza, MA, RN:

No, I think you did an excellent job, Jessica summarizing kind of the key areas that palliative care can provide support. It's got helping support with decision making, with maybe setting the goals of care, but also related to pain and symptom management are huge as well. Although I do remember that at the beginning, I thought that that would be the thing that we would be called about the most was trying to help with pain and symptom management. And certainly we do, and that's a big bulk of our work. Certainly, a big bulk of our outpatient clinic work is patients coming back to our clinic, because they do have symptoms that need to be addressed.

Maureen Giacomazza, MA, RN:

But I would say that the majority of new consults that we get is really to help guide goals of care discussions and to really help with decision-making. Those are still really the largest reasons why we get called. But you summarized those things really nice.

Maureen Giacomazza, MA, RN:

But the thing that I really want to make sure that all nurses understand is that palliative care, while it is a specialty, and while we can lend special help, all nurses provide palliative care. You are our frontline palliative care providers. And I think that's why palliative care resonates so much with nurses is because it's at the heart of what we do as nurses. It's what we know as nurses.

Maureen Giacomazza, MA, RN:

I remember when I was first going to national palliative care conferences in the early '90s, and this was when it was a new specialty here in the United States, people would get up and give this definition of palliative care. And they would say, "Palliative care deals with the mind, body, and spirit of the patient." And they talked about this as if it was like, isn't this amazing, this is like a new thing. And I would kind of sit there and want to raise my hand and say, "That's nursing. That is what we have always known in nursing." We have always dealt and supported the mind, the body, the spirit dealing with the psychosocial and biological person, it's nursing.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Oh, it's so inherent in what we do.

Maureen Giacomazza, MA, RN:

It is. And so own that. Own that, for sure. When you think of yourself as a nurse, I want you to always remember that you are a palliative care nurse. Reach out to the team when you need, maybe some advanced expertise and symptom management, or you really can't get your team to be on board with what the goals of care are. But most of that, you can do yourself. You should feel empowered as a nurse to call that family meeting, and say, "It's unclear to me what the goals of care really are here," or, "I'm hearing a different thing from what the family really wants, and what the team think that the family and patient want." You are the frontline palliative care providers. It is the heart and soul of what we do as nurses.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Oh, I love that point, because it's so true. It truly is really the foundation of our education and everything that we learn. I totally agree. So I think it would be a missed opportunity if I didn't talk for a minute about the fact that it's not natural for children to have serious illness. It's not natural for children to die. Especially, I think, in our society where we have such great advances in medicine, we have technology, we've got so much to offer patients and families. And so I think it's even less common for us to experience death of children.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

But I'm curious, Maureen, having done this work for a prolonged period of time and supported families through what are undeniably the most difficult days of their lives, what kinds of pearls would you share with nurses who want to do this work, but also struggle with the fact that this isn't natural and it's hard? It would feel almost impossible for this not to hurt our own hearts or weigh heavy on our own selves, even though we are the professionals in the situation.

Maureen Giacomazza, MA, RN:

Yeah, for sure. I think it is hard, but sad is not bad. You come home and you have a bad day, it's hard to sometimes shift gears when you are in the room with a family who is actively grieving. And then I would come home to my own two kids who expect dinner on the table. And how do you stay resilient through that? Obviously, there's all kinds of help and support out there. Alls you have to do is Google in nursing resilience, and there's apps you can use, there's tips. Our social worker on our team is just wonderful for trying to... she'll read a poem of the day or she'll help us suggest, just sometimes you just got to remember in the moment of a crisis to take a deep breath.

Maureen Giacomazza, MA, RN:

I would sometimes find myself in the middle of a code in the ICU. And all of a sudden I realized that I was holding my breath. And so sometimes, especially in the moment, you just got to remember to breathe, take a deep breath, maybe focus on your feet, feel the ground, again, underneath your feet. Obviously, debriefing with colleagues is huge. You need to be able to share those burdens and those struggles, and just talk about it. But, also, I think I was able to stay somewhat resilient and continue to work in that, just because I consider it such an honor and a privilege to be with families at their worst, and be able to feel as if you can try to make that a little better.

Maureen Giacomazza, MA, RN:

There's nothing more I can say other than, it just being such an honor and a privilege to be there. And I mean, that is what the very word compassion means. It is bearing witness to others suffering and to being with them. And we know that nursing presence is huge. You don't even have to say a word just being present in the room is enough to support families, oftentimes. In fact, sometimes it is good not to say anything and just have those moments of quiet. You don't always have to have the wise words at your fingertips, just being there. Before the days of COVID, we'd give lots of hugs to each other and that always helped me, is just making those personal connections with people. So that's what always just helped me.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

I appreciate that. It is such a unique opportunity. When you think of any other profession, it is something very unique and sacred, I think, to nursing that-

Maureen Giacomazza, MA, RN:

Yes.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

... you get to be part of that, you know?

Maureen Giacomazza, MA, RN:

Yeah. I have often used those words about what a sacred space that is, and just looking at it as such a privilege and an honor to be in that space. What I would say, too, I would certainly want to say, it took me a long time as an ICU nurse, and I don't think I really got it, until I became a palliative care nurse, of the different spaces that families can be in at the same time.

Maureen Giacomazza, MA, RN:

So let me give you an example of what I mean by that. Sometimes we may have to give bad news to the parents that, perhaps, their surgery hasn't gone as planned or they're now refractory to their chemotherapy, and their disease has progressed and we're giving them this bad news. And then they make a comments of, after all of that and there's tear and you go back to the room and the mom says, "Well, when he goes to first grade, blah, blah, blah." And you think, "Oh my gosh, they didn't get it. We just sat in the room for an hour telling them that their child is going to die. And the disease has progressed. And now they're talking about when he goes to first grade. They don't get it."

Maureen Giacomazza, MA, RN:

And what do we do? How do we respond to that? We think, oh, they didn't hear us. We better give them more medical information. And we continue to shove more and more medical information at them. And it took me a long time to realize that this is not denial. They did hear what we said, that those expressions of, "Well, when he goes to first grade," or, "At his birthday, were going to plan this party," it doesn't mean that they didn't hear you, it doesn't mean that they're in denial, they're just expressions of their heart, their expressions of hope. And as long as you live in the land of the living, you will always have those expressions of the future.

Maureen Giacomazza, MA, RN:

And I don't know why it took me 30 years to understand that. I always hope I'm going to be skinny at the same time, I'm eating chocolate chip cookies with my two boys. So I live in those two worlds, and so do parents, so do spouses, so do siblings. As long as you are in the land of the living, you hope for a future, and children, too, even dying children. I once visited a patient that I had followed for many years at hospice. And she shared with me that she had planned out her whole funeral, she picked out what songs were going to be sung, and which readings she wanted from the Bible that had significance to her. And then she started to talk about her boyfriend, and, "Well, someday when we get married and when we have children."

Maureen Giacomazza, MA, RN:

She wasn't in denial of her dying. She was in hospice. She had just told me she had planned out her funeral, but she was still in the land of the living. And as long as she was there, she wanted to hope that one day she would get married and they would have children. It just took me a long time to understand that fully.

Maureen Giacomazza, MA, RN:

So I'm hoping I can save your students 30 years of experience in order to grasp that. But when people say that stuff, I think alls you can do is just express back that you hope for that too. That's all you need to say. You don't need to think, oh, my gosh, and run to the attending physician, and say, "They don't get it. And we have to have another meeting and tell them more medical facts." They say a hope for the future, just simply say, "I hope for that too."

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

I'm so glad that you shared that, Maureen, because I do think it's such a valuable lesson. I think that rather than respond seeing that as a red flag, and like you said, with this desire to make sure that they are abundantly clear about the news that we just offered them, I think, to afford them that opportunity to live until they die-

Maureen Giacomazza, MA, RN:

Yes.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

... rather than just force some other outcome or reality upon them, I think is such a beautiful opportunity that nursing has too. And I think that that's a lot of what palliative care does, too, is let people and empower them to live until they die, right? So-

Maureen Giacomazza, MA, RN:

That's right.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

... if we can tackle that elephant in the room, then what is important to you? Then what could we do that's meaningful for the next week? Or-

Maureen Giacomazza, MA, RN:

That's right.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

... the next month? And I think as nurses, we have such an important opportunity to let there be great life in those days that are left, rather than focusing so much on the fact that that death is inevitable. And-

Maureen Giacomazza, MA, RN:

Yeah, I agree. I mean, because hopes are not just one big monolithic thing. A hope isn't just for the cure, there's lots of other little hopes. So when a family says, "Well, we're hoping for a miracle," again, you say, "I hope for that too." And then you can say, "What other hopes do you have?" And they will start to tell you those other things, like, "I hope they can go outside one more time," or, "I hope that grandma can make it here from California in time," before they die."

Maureen Giacomazza, MA, RN:

They will start to unpack all their other hopes. And those are the things that you, as the bedside nurse, can work on. You can start to help them achieve those other hopes. If it's going outside, that's huge, and pack them up. I packed up many ICU patients and put the drips on the bed and things like that, and get them outside under a tree, if that's their dying wish. So you can make a difference and helping them to achieve their other hopes.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Maureen, this has been such an inspirational conversation. I'm so glad that we've had this. I hope that nurses who find themselves in the shoes that we've walked in and the opportunities that we've had as we've cared for children and families over the years, I hope that they can listen to this too and know, one, they're not alone, and, two, their work is so highly valued, and has such an impact on families. And I'm just so grateful for you sharing all of this insight. Is there anything else that we didn't get to, or that you wanted to share with as we wrap this up?

Maureen Giacomazza, MA, RN:

I don't think so. I think, you reminded me I know that nurses week is coming up, starting this week and into next week, ending with Florence Nightingale's birthday. And I think, I would want your students to always be inspired, not only by those kind of nurses the Florence Nightingales of the world, but realizing that there are everyday heroes, find out what inspires you, look at those, look at those nurses, what are the qualities that they have? To just really seek that out and to always realize, and I hope, again, that they always feel empowered to know that they can make a difference. It might not happen fast. Like I said, it took me a long time. I mean, that was six years of just planning to get the palliative care program up and running, that still didn't even count in my years of studying bioethics first, and then sitting on the ethics committee. And I felt like that wasn't quite the right answer to talking about the pink elephant number.

Maureen Giacomazza, MA, RN:

So, I mean, it was the better part of a good 15 year journey for me to figure that out. So be patient with yourself, but don't give up, your ideas are important. I often think of that quote by Helen Keller that I think is so lovely, and she said, "I am only one, but I am still one. I cannot do everything, but I can still do something, and I will not refuse to do the something I can do." Thank you again for inviting me to spend this time with you and your students. I really appreciate of the opportunity.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Well, thank you so much. I so appreciate all of your insight. And as I said, this wisdom and the words that we can offer families, I really appreciate you taking time for us today, Maureen. Thank you.

Maureen Giacomazza, MA, RN:

Okay. Take care.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Bye.

Maureen Giacomazza, MA, RN:

Bye.

Jessica Spruit, DNP, RN, CPNP-AC, CPHON, BMTCN:

Thank you for listening to this episode of Nightintales. As you do, we encourage you to consider the unique nature of each person's journey through this profession. The views shared on this podcast are those of an individual, not the academic institution that they graduated from, their employer, or the professional organization that they're active in. The stories of their career path and progression are not intended to suggest that there is a uniform approach to achieving similar accomplishments, but to open your mind to all that is available to you. Each journey in nursing, is as unique as each individual that we serve. We hope you'll listen again next time.