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Welcome to NETWise. This is a podcast for neuroendocrine cancer patients and caregivers that presents expert information and patient perspectives. My name is Melissa Phillips, from the Neuroendocrine Tumor Research Foundation.

NETRF recently did a survey among our patient community of what topics they'd like to learn more about, and one subject rose to the top of the list: supportive care for NET patients - finding and using professional medical care that doesn't attack the tumors directly, but rather deals with all the other issues that affect a patient's quality of life. These might include managing symptoms and side effects, managing pain, and dealing with the psychological and emotional ramifications of living with a serious illness.

The good news is that all of these important topics, and more, are addressed by a dedicated multidisciplinary team of professionals at most major hospitals and health centers. They are ready and willing to help improve the lives of patients in a myriad of ways - and yet, it's a team that many patients are hesitant to reach out to. This is due to deep misunderstandings about what these providers do and how they do it.

We're talking here about a palliative care team.

What's the first thing you think of when you hear the term "palliative care"? I wouldn't be surprised if your mind immediately goes to hospice and end-of-life care. The truth is, though, that palliative medicine doctors and their colleagues do much, much more than that, and have a lot to offer to NET patients who may live with their disease for a long time.

Here's Abraham Labrada-Santiago, a palliative care Chaplain at the Mayo Clinic in Rochester, Minnesota, followed by Dr. Steve Pantilat, Chief of the Division of Palliative Medicine at the University of California, San Francisco:

Labrada-Santiago: *"And I think that's the main misunderstanding. Some people who listen about palliative care are like, 'well, I'm not ready to give up'. We are not giving up either. Our goal is to provide them with quality of life, and I think people who understand that part benefit a lot from palliative care."*

Pantilat: "I think of palliative care as medical care that's focused on improving quality of life for people with serious illness. And what I tell my patients is look, I'm not an expert in neuroendocrine tumors, right? That's not my expertise. You have an expert for that, but what we try to become an expert into is YOU as a human being. And our focus is on, you know, understanding what's important to you, helping you make really good decisions about your treatment and what's important in your life and how you spend your time, to support you and your family, and to treat the symptoms that might come up from your illness or from its treatment."

And here's Dr. Sandy Tun, a palliative care physician at the University of Chicago:

Tun: "We can be involved from the day that you're diagnosed with your serious illness. And we're right there with you as you're going to your chemo appointments. We're right there with you as you're talking with your cardiologist, talking with your surgeon, as you're thinking about that big surgery. We're kind of there by your side as that extra layer of support."

Something else that people don't always understand about palliative care is that it is a recognized medical specialty with its own training programs and certification.

Pantilat: "I think sometimes people think that palliative care is just some people being nice to you and sitting by

your bedside and holding your hand, you know. But it's medical care, which is to say it's expert symptom management. It's really being able to address your pain in a really expert and nuanced and refined way, or to treat nausea or to try and improve fatigue or shortness of breath."

But real quality of life goes beyond medical issues like symptom management. This is why palliative care is often provided by integrated teams, consisting of doctors, nurses, social workers, and chaplains - who together focus on a patient's total wellbeing.

Pantilat: *"Palliative care really is provided by a team and we contribute equally to the care of patients because of the range of issues that we are trying to address.*

To improve your quality of life means it has to go beyond the medical and it has to go beyond the illness, right? It has to treat you as a human being and all of you as a human being and all of your concerns. So your psychological, and emotional, and spiritual concerns, your family, your caregivers, and of course your medical issues as well."

Labrada-Santiago: *"One of the basis of palliative care is the concept of total pain, which is social pain, physical things, psychological pain, and spiritual pain.*

The interdisciplinary nature, the transdisciplinary nature, of palliative care allows us to work together - myself as

chaplain and the physician and the nurses and the social workers to make people live as long as they can, as good as they can. And that's a cliché that a lot of doctors will say, but I think it's true. I think when you're able to nurture all those aspects together, people do better in general."

Another myth about palliative care is that once you begin receiving it, you have to continue to do so until the end of your life. This is completely untrue.

Tun: *"So there are patients who I see where I may be taking care of them while they're going through chemotherapy, while they're going through their different treatments. But then once they're in this place where their symptoms are better controlled, where they're not necessarily making those major milestone decisions about, you know, chemotherapy, surgery - you know - transplant, dialysis, and they're actually, you know, in this kind of watch and wait kind of period, or in some really wonderful cases, cure, they no longer have to see me. They kind of graduated out of needing that palliative care support."*

And the positive results for patients receiving palliative care are well-documented. A landmark study done at Harvard in 2010¹ demonstrated that cancer patients receiving dedicated palliative care on top of treatment for their cancer did better in a myriad of ways.

¹ <https://www.massgeneral.org/cancer-center/clinician-resources/advances/the-meaningful-benefits-of-early-palliative-care-for-advanced-cancer>

Pantilat: "And this was in people with lung cancer. Everybody got standard chemotherapy at Harvard. This was done at Massachusetts general hospital, so they got good cancer care. And then half the people randomly assigned to get palliative care in addition. What did they find? Basically, everything good you want to have happened to people happened to those who got palliative care. Which is to say they had less pain, they had less shortness of breath, they had a better quality of life, they were less likely to be depressed, and they lived longer than the people who did not receive palliative care.

So, you know, if this was a drug, like if we had a pill that would do that, everybody would take it, right? You'd give it to everybody. Why not? Right. You feel better. You have less depression, you have better quality of life, less pain, and it helps you live longer. That's amazing. Oh, by the way, no side effects, no negative side effects at all. And so that's what I would tell people, you know, 'you'll feel better'. Don't be afraid of palliative care, embrace it."

Redding: "My name is Richard Redding. Most people know me as "Spike". I'm 75 years old and I live in a place called Cameron Park, California, about 35 miles east of Sacramento. I was originally diagnosed with neuroendocrine tumors in 1993, and I've had them ever since.

I get Sandostatin shots every 28 days, and I've been doing that since 2000, so my butt's kind of like a pin cushion. In 2017, I was also diagnosed with renal cell carcinoma. I have some metastasis to my lungs from the renal cell carcinoma, and I've got metastasis all through my abdomen and I've got tumors on my liver from the neuroendocrine tumors, so that's kind of where I am today.

So about 2017, 2018, somewhere around there, in December of that year, when they were going to put me on a fourth chemotherapy, I said, 'I don't want to do any more chemotherapy.' I was tired. I had lost about 60 pounds on chemotherapy and I was just kind of worn out. I went to the VA. The head of oncology for the VA had me go to a palliative care doc and the palliative care doctor is in the same area there with them. And we talked about the chemotherapy and what to do as far as what I wanted to do and what palliative care would do for me. And then I contacted, also, Medicare and they sent me up with a palliative care group.

The Medicare person, they come and see me about once every other week or so. They'll come in and talk to me and see how I'm doing, and the nurse actually comes to the house, checks my vitals and that kind of stuff. And the palliative care docs at the VA, I do telephone, uh, Zoom-type calls with them probably once every four to six weeks.

Through the palliative care program, I feel that I have more say in what I do. And they listen to me more. They're

not worried so much about what my diagnosis is as to how I'm doing and what steps I want to take or where we're going to go from here. So I have that increase in... invisibility, I guess you could call it, with palliative care."

A good palliative care team provides several important functions in the care of a NET patient - let's look at some of these one-by-one.

The care team for a NET patient often includes a wide range of different specialists: oncologist, surgeon, gastroenterologist, endocrinologist, and more. One of the roles of a palliative doctor is to act as an interpreter between the patient and the rest of the medical team. This is a translation that happens in both directions - making sure the rest of the physicians understand the wants and needs of the patient, and also that the patient understands what all the other clinicians are saying and why.

Tun: *"Oftentimes, patients and families, they're inundated with floods of information from all the different specialists in their life. And oftentimes, they're having a hard time sifting through what's the best option for me moving forward. We become, in many ways, the communication experts."*

Pantilat: "You know, taking the information that my oncology colleagues will say, and then sharing that with the patient, and then moving in the other direction, 'Hey, this is what's really important'. In part because, you know, my focus in talking with patients is like, 'What's most important to you?' You know, when I'll ask some questions, like, 'When you look to the future, what do you hope will happen? When you think about what lies ahead, what worries you the most?' And I think those are really important questions that I ask, and then I understand what's most important, and then I can share that back with the oncologist and say, 'Look, this is the most important thing. So it sounds like this path might be better than the other.'"

Sometimes, this translation can start to look more like advocacy.

Tun: "Yes, there are times when, for example, the oncologists will tell me that, you know, we want to suggest this additional line of chemotherapy despite the recurrence or despite the progression of the disease; or we want to enroll the patient with a clinical trial, we'd like to move forward with that. And I have had quite a few instances when after talking to the patient and family and understanding a little bit more about what their quality of life looks like and what their functional status looks like - and by that I mean what are they able to do in their day-to-day life - I've gone back to the oncologist or whichever

referring specialty and saying, 'I think we need to take a step back, or we need to pump the brakes.'"

The primary medical function of palliative care doctors is the management of symptoms and side effects - making sure that patients aren't suffering unnecessarily from all the challenges that come along with cancer diagnosis and treatments.

For NET patients, these symptoms are often uncomfortable, embarrassing, and sometimes debilitating challenges of the G.I. tract - things like nausea, cramping, constipation, and diarrhea.

Pantilat: *"Nausea, appetite, diarrhea, constipation - those can be difficult to manage, but there are lots of different treatments for all of those."*

Tun: *"It becomes this stepwise process, where oftentimes I'm starting with something like a Creon to see if that helps, just so that we're replacing those enzymes and you're only taking it with meals. And if that doesn't work, then oftentimes we're adding on top of that something like Imodium, which is over the counter. Beyond that, we're looking at things like Limotil, for instance, which we have to prescribe."*

In addition to the pharmacologic things that I'm suggesting, I'm also thinking about asking people, 'How are you sleeping? How are you eating? What's your mood been

like recently?' And oftentimes that becomes a jumping off point to talk about the stress, the anxiety, and quite frankly the trauma that people go through as they're going through their treatment. And all that trauma adds up, you know? It releases stress hormones into our bloodstreams. And so that's often that Irritable Bowel Syndrome-like constellation of features where, you know, your gut may be a little out of sorts related to anxiety."

Another set of symptomatic treatments that come under the purview of palliative care are pain medicines, which, of course, can also be bound up with the general trauma of undergoing cancer treatment.

Pantilat: *"In talking to people about their pain, the first thing is to really understand what is causing the pain. Not all pain is the same. Is it pain generated from nerves? Is it, you know, pain because there's cancer in your bones? Is it pain from cancer growing in a particular place? Is it pain that's not related to your cancer? Not everyone with cancer or neuroendocrine tumor has pain because of that reason, you know? There are other sources. I have some people with back pain, just bad low back pain, so there's lots of things going on. The first is to really understand it, and then to think about what's the simplest way that we can manage it.*

Sometimes people come to palliative care and I say, 'Well, you haven't tried acetaminophen, Tylenol.' Sometimes that's enough. And if that's enough, that's great. It has a really

good side effect profile. The one thing I will say for people who are listening, if you have any issues with your liver you should really talk to your doctor before that because high doses of acetaminophen can cause a problem for your liver. For most people, it's fine and it won't be a problem. "

There are also many integrative, nonmedical treatments that can be really effective for pain.

Pantilat: *"Treatments whether it's, um, acupuncture, massage, mindfulness, those can be really, really helpful to feel better, to ease their pain, to make the pain easier to, to manage."*

And if these methods don't work, of course there are stronger pain medicines. Opioids and other prescription pain medications are a sensitive subject due to their well-publicized misuse. One of the big advantages of working with a palliative care team is the active supervision of a doctor who is an expert in the safe use of these medicines, so you can make sure you're getting what you need and avoiding what you don't.

Tun: *"There's lots of different opioids to choose from, but let's start you on maybe, you know, that second level of pain management, you know, one of our less potent opioids. That's my approach at least. And then let's see how you're doing on that. God forbid, if that pain isn't managed we'll have to escalate you as needed, you know, through those ranks."*

My goal is that we have open and honest conversations about how you're using this medication. And so one of the things I'll ask folks to do is, you know, I'll have them keep a pain log, whether it's electronic on their phone or in their notepad where they'll keep track of how much they're taking and then you can say with certainty, 'I've taken this many tablets because I've been keeping track.' And then the hope is that as the pain is getting better, as your pain log is showing that you're needing less and less, we're able to get you off of that medication."

For some patients, the fear of misuse of these drugs causes them to avoid their use altogether. This fear is understandable, but if the pain you're experiencing is so severe that you're unable to function, it's really important that you get help.

Tun: *"When we think about quality of life, in my mind it is unacceptable for someone to be in such extremis when it comes to pain that they're not able to live their daily life and spend time with their family, or, you know, do the hobbies that they enjoy doing. And so when someone says, 'I don't want to take any medicines,' but then I find out from them or their partner or their friend that they're essentially bedbound because any sort of movement causes pain, I say, 'I think we need to have a serious conversation about that.' My usual approach is that I think we should try to make sure that you're using the lowest dose you need for the shortest amount of time possible."*

A big part of the safe use of pain medicine is understanding what abuse really looks like.

Pantilat: *"Safe is: I take this medicine and I am more functional than I was before. So, before I was having so much pain, I had trouble getting out of bed. It was hard to dress. I couldn't bathe. I couldn't go for a walk. Now I use the medicine, I can go back to work. Now that I use the medicine, I can get out of bed more easily. I can walk better and farther. So, if you become more functional, more alert, and more able to interact with my children because my pain is controlled, that's good. If what happened is I used these medicines, now I can't go to work because of the medicines. Now I don't get out of bed. Now I'm irritable and I don't want to talk to people, that's a problem."*

With all symptom management, be it for pain or things like diarrhea, every patient is different, has different needs, and responds differently to different medications, so finding the right treatment often involves a lot of trial and error.

Tun: *"Especially with, with diarrhea, it can be, you know, a lot of, 'oh, we've gone too far, that medication has maybe stopped you up too much... That's not enough...' It's like parallel parking in many ways. At first, you're doing a lot of big moves to try to, you know, position yourself. But then when you're trying to find that exact tailored dose and regimen for the patient, it's just like parallel parking where you do those big moves first and then at the very end, you're just trying to nudge it in. So you're*

doing, like, little adjustments. And so oftentimes that's, that's what it looks like.

Patients will say, 'It feels like, you know, we're just testing things. Why don't you have a set answer for me?' And the thing I always bring up to patients is that, going to medical school, I have the textbook and the expertise for people in general, but no one gave me the textbook and expertise for your particular body. So even though I have that expertise and I know which medicines work, I know which receptors work, I know the research behind each of these medications, I don't know what's going to work for you. So I always tell patients that's the reality of what we're looking at, and so even though it seems like it's trial and error it's really because we're trying to tailor the regimen to you."

Howard: *"My name is Laurel Howard. I live in west Chicago, Illinois, which is a far west suburb of the big city, and I just had my 18th 'cancerversary' as I call it. I was diagnosed with neuroendocrine lung cancer back in 2003. I had a surgery in 2003, and then I had a second surgery in 2010 in the same spot. And, uh, now it's metastasized into both of my lungs. I have pancreas and those are the big spots. And then depending on how well the CT scan picks up, I've had spots come and go in the liver, the adrenal gland, they thought maybe there was one on the thyroid, you know, it's kind of... I'm a mess (laughs).*

So, I have pretty regular carcinoid syndrome episodes, and that's kind of what led me to the palliative. So I've been going to see my palliative care people, oh, about five years. I have to tell you that I was the one who initiated that. How I came to that is one of my very good friends from college is a palliative doctor out in the Tacoma area, and so I know from my friend what palliative care means. And I was, to be quite honest, I... it was a struggle for me to wrap around what was the realistics of my care. If I'm going to live with this, as they say, as a chronic form of cancer, how best can I live my life?

The palliative people, they really were good at identifying what were my triggers. Some of it can be exercise-based. Some of it can be food-based. What were the emotional triggers? What were the things that I could have control over? This, for me, was very helpful in helping in making sure that I felt like that I can do what I want to do, given the limitations that I have. I found that it's the one place where, in essence, it's all about me. The appointments are never rushed because they want to know how I'm doing. They want to know what I'm eating. They want to know what I'm doing for fun. They want to know how my family is responding. I've just found it to be exceedingly helpful. No pushing to try one thing or another because you have to know what is going to work best for you.

Well, like I said, I'm now in my 18th year of this. You can live a long life sometimes with this. So it's a chronic

situation and you've got to figure out how you're gonna live your life. Do you want to stay at home complaining all the time? Who wants to live like that? This cancer can be very wearing on a person emotionally, and the palliative for me has helped me choose what I'm going to do and how I'm going to do it. And that has... I found that to be very freeing."

Living with cancer has many challenges associated with it, and many go far beyond physical symptoms. It's an enormous emotional challenge, also, and palliative care teams recognize that in order to improve someone's quality of life, they have to address their mental and emotional pain just as much as their physical pain.

Pantilat: *"A serious illness diagnosis really is devastating. You think you're going to die when you get the diagnosis and it's really distressing."*

Tun: *"It does feel like life or death each day, because it is it. We're talking about your body and we're talking about what's going on with it, and we are talking about your life and potentially your illness, your decline, and potentially your death, and all of those things are traumatizing."*

Pantilat: *"And, you know, and it's okay to feel sad. That's the other thing, sadness is totally appropriate. And I worry for many people that there is this sense in our*

society that we have to be really positive and, you know, have a positive attitude. And I even write about this in my book, that I worry that this idea that somehow positive attitude will make us better. And therefore, if you don't get better or things get worse, that you didn't have the right attitude just puts too much burden on people. You know, you're allowed to be sad. You're allowed to sit there and just start crying because you don't feel well, because the future you thought you had is different. That's normal. You're just human, and you're absorbing the reality of your situation. That's okay."

There's a difference, though, between sadness and depression. Another huge benefit of palliative care is having expert help in understanding that difference, and finding ways to feel the feelings you need to feel without slipping into a place of unnecessary mental anguish.

Pantilat: *"Depression is, you know, it's an illness. It's a diagnosis that is related to imbalances in chemicals in the brain, and that can be treated and improve. If you actually get depressed, which is to say a clinical diagnosis of depression, that's not normal, and that is treatable, and it's treatable even in people really close to the end of life with really advanced illness."*

You know, sometimes people say, 'Oh, who wouldn't be depressed if they were dying of X?' And the answer is, uh, most people. Most people are not depressed. You know, if you have depression, meaning you feel hopeless, you're not

able to do anything, you feel helpless - that's a suffering that's added on top of the suffering that you might have from your illness and should be treated."

There is an underlying concept here of the difference between necessary and unnecessary suffering, and helping address that difference is where the nonmedical members of palliative care teams - counselors, social workers, and chaplains- can really shine.

Labrada-Santiago: *"People who are going through a lot of suffering, they lose meaning there, they enter into despair. In that we have to do a lot of interdisciplinary teamwork, because when I see somebody with despair, I understand things that are going through, but sometimes they still have the possibility to make meaning.*

Even when somebody is going to a difficult illness - extreme cases where, you know, there's, the symptom burden is too high - most people can reframe it, but they need the help. Otherwise they will be in despair. And one of the things that we want to prevent is unnecessary suffering. Despair that tells them 'There's no meaning in life. Why is this happening to me? I don't want to keep going.' So that's the unnecessary part of it, where they're going to go through suffering, but patients usually do better when they can grab onto what is meaningful to them."

This kind of help often moves past the medical and even the mental and into what can only be referred to as spiritual care.

Helping patients find their place in the world, now that their lives have changed so dramatically.

Labrada-Santiago: *"Illness is a spiritual event, because significant illness will transform and will change a person forever."*

Pantilat: *"When we talk about spiritual issues, I'm not really talking about religious issues, although those are important as well, but it's really issues about the spirit, about the soul, about legacy, about relationship, about meaning in my life. And those are the kind of more existential issues that people really are thinking about and want to talk about. And that our chaplain's really expert at."*

Labrada-Santiago: *"There's religious chaplains - we have Buddhist chaplains, we have Muslim chaplains. I'm endorsed by the Orthodox Church, which is a Christian-based orthodox church. We have chaplains who are humanists nowadays, as well. All of them are striving to meet the people where they are at. We are very inclusive and very embracing of any kind of a spiritual practice that anybody will have here in the hospital. So we are here to kind of connect people with what is sacred for them. It doesn't have to be a religious thing. We know that people that are going through difficult illnesses are struggling, not only physically, but also spirituality... in their spiritual life, so we want to take care of those parts as well as the physical part."*

So what are the things that I do? I can pray with them. I can talk to them. I can explore some of the existential questions that people come with, which are, 'Why is this happening to me? Where, where am I going? How can I deal with this?' We don't have answers for those questions, I will say, but we do try to see what is the root of the question.

A lot of people who are going through difficult illnesses, they feel like they have been abandoned, especially if they have a religion. They believe sometimes they believe they're abandoned by God. They're angry at God, or they're angry at life sometimes. So we're able to talk about these conversations and just reframing where does that anger come from, or where does that grief center to. I think it has been very helpful for some patients. So I think that ability to be with them and to honor this sacred.. sacred life, and connect in that very human way is what is important for me.

Crane: *"My name is Roseanne Crane. I live in the San Francisco Bay area. My husband had a very aggressive form of neuroendocrine cancer.*

When he was diagnosed, he was assigned a symptom management doctor who is a palliative care doctor. He had a wonderful medical oncologist. He also had a fantastic surgeon and a very fine radiation doctor, but the relationship with the symptom management doctor was entirely different. With the

other doctors in his cancer care team, they were all centered on the treatment, and understanding the treatment, and what the alternatives were, and how to make the next decisions in his care. With the symptom management doctor, the palliative care doctor, it was entirely about the things that had become most important in our life. They were the messy, unpleasant things - eating, sleeping, and eliminating. It was very much like a baby in the first six months of life. It was the most basic things that the palliative care doctor helped us with.

She had much more time, so she got to know us and got to know us as people above and beyond Ron's illness and symptoms, and helped us with the very real day-to-day issues that we were grappling with rather than the bigger picture of what the treatments were. With chemo and with the pain medication, constipation is a huge issue, and we had ended up in urgent care more than once because of it. They dealt with that issue. He had no appetite and knew he had, and they helped him with that. And he didn't really want to deal with pain or the fact that he was in pain and wasn't sleeping every day, every night, it was a 24-7 problem.

I don't know what else to say except that my husband was a very typical guy, independent his entire life. He had been a very successful entrepreneur. He was always used to being in control and telling other people what to do. His body had never failed him in any way prior to this. I thought it was important for him to have somebody he could talk to

about these things that he found very embarrassing. In terms of day-to-day functioning. They were incredibly important."

The bottom line here is that palliative care can be a tremendous help to anyone facing a serious illness, at any stage in their disease. This is because palliative care physicians can spend the time to concentrate on issues that other doctors just don't have the expertise or even bandwidth to consider, and therefore provide help that no one else can.

Tun: *"I think it would be fantastic if an oncologist or a surgeon would also have enough time and space in their schedule and in their appointments to have these conversations - In addition to talking about the chemotherapy or the clinical trial or the surgery, also have time to talk about symptoms and talk about everything from a physical and psychosocial standpoint that the patient is going through as well. In an ideal world, you know, all of my colleagues would have that luxury. But the nice thing is as a palliative care doctor, I have that protected time and protected space in my appointments to have those conversations and bring up the things that you're afraid of, bring up the things that are impairing your day-to-day life."*

Pantilat: *"I tell people, when I see them in my clinic, is my job, our job as a palliative care team is to help you live as well as possible for as long as possible. And I*

really see that fundamentally as the goal of medicine, but certainly our goal in palliative care. And it really is an opportunity to just think about what that really means for each of us as individuals. What does that mean to live as well as possible? And it's an opportunity to really engage deeply with that question about what's important to me - Who are the people I like to spend time with? How do I want to spend my time? - and to make sure that we're doing that... each of us should be doing that every day, anyway. But when you look ahead and you think, oh, you know, I've got a long, long time, I don't have to worry about that now. Serious illness really brings that front and center.

You know, there's a great poem, 'The Summer's Day' by Mary Oliver, that ends, ' Tell me, what is it you plan to do with your one wild and precious life.' And I think about that a lot."

Thanks for listening to NETWise. My name is Melissa Phillips, and I'm Director of Communications for the NET Research Foundation. This episode was produced by David Hoffman of CitizenRacecar. It was made possible by the generous support of Ipsen Biopharmaceuticals, Advanced Accelerator Applications, a Novartis Company, TerSera Therapeutics, and Lantheus Medical Imaging. Special thanks to everyone we interviewed for this episode. We are grateful for your expertise. This is a production of the Neuroendocrine Tumor Research Foundation, where we're committed to improving the lives of patients,



Episode 15:
Supportive Care for the
Mind, Body, and Soul
Transcript

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