

## Support For Patients and Families At Any Stage of Serious Illness

Webcast

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### **Introduction**

#### **Andrew Schorr:**

From relieving pain to managing anxiety, the goal of palliative care is to improve the quality of life for people living with serious illnesses. Working with a team of specialists, patients and their families can receive a broad range of support at any stage. Coming up, a leading expert in palliative care will discuss who can benefit, plus a patient will share his own experience. It's all next on Patient Power.

#### **Andrew Schorr:**

Hello and welcome to Patient Power, sponsored by Northwestern Memorial Hospital. I'm Andrew Schorr.

So often we talk about treatments for different illnesses, and obviously if possible you want to cure the illness. Now, that's not always possible, so then you want to have the illness be kept at bay, if you will, for instance with cancers or other illnesses as best you can to be managed. Sometimes they progress, and along the way you're always thinking about quality of life. Yes, you want to treat the illness, but you want to live as full a life as you can, too.

Well, there are teams, for instance at Northwestern Memorial Hospital, and physicians who specialize in that, and that's what's called palliative care. So we're going to understand how palliative care can help people with long-term, serious illnesses have the best quality of life possible.

### **Don's Story**

Now I want you to meet someone from right in the center of Chicago, Don Lartz, who has sought palliative care, and it's been helping him. Don, you are 66 years old. Is that right?

#### **Don:**

67.

#### **Andrew Schorr:**

67 now, okay. And I know for many years you smoked a pack of cigarettes a day, and as we know sometimes that can lead to breathing problems. For you it was emphysema and ultimately COPD, and I guess over the years the COPD has been getting worse?

**Don:**

Yes. It's progressing.

**Andrew Schorr:**

And so you live alone, and so you're on oxygen now 24 hours a day?

**Don:**

Pretty much, yeah.

**Andrew Schorr:**

Okay. But you still try to do things. You volunteer at a senior center?

**Don:**

Yes, one day a week.

**Andrew Schorr:**

Okay. And I know you had gone on to get a master's degree. For years you were in the food service industry. So thinking about making every day as good as it can be, that's your goal, right?

**Don:**

Yes, it is.

**Andrew Schorr:**

So tell me about palliative care. Where did this come into play? You have pulmonologists and other doctors to help you with your COPD, but what about this idea of palliative care? Where does that come in?

**Don:**

Well, it's another doctor that I can talk to. Sometimes I forget or don't have time to mention things to my primary care provider or my pulmonologist, and I can tell that to the palliative care specialist. Also, they're like a friend, you know? I have a little closer relationship with the palliative care specialist, you know, and we do a little bit more talking. And for someone like myself who lives alone, and I don't have a lot of people to talk to, this is exactly what I need. I think of Dr. Szmuilowicz as a combination of doctor, you know, internist, sociologist and psychologist.

**Andrew Schorr:**

Now, I know that along the way you've dealt with anxiety, and I'm sure having difficulty breathing can be scary. So did the doctor help you with your anxiety as well?

**Don:**

Yes. You know, when you have a disease like this you feel more vulnerable, and you start getting a little jumpy, and the littlest thing sometimes can bother you. So talking to the palliative care specialist has helped calm me down and given me more confidence.

**Andrew Schorr:**

Well, let's meet your doctor who is a palliative care specialist. You mentioned him. That's Dr. Eytan Szmuilowicz. Dr. Szmuilowicz is an assistant professor of medicine. He's an internist in the division of hospital medicine at Northwestern Memorial Hospital, and he's a subspecialist in palliative care.

Doctor, thank you for being with us, and I know it's great to hear Don sing your praises that you're making a difference there.

**Dr. Szmuilowicz:**

Well, thanks for having me, Andrew.

**What is Palliative Care?****Andrew Schorr:**

So, Doctor, what is palliative care? So many of us are not familiar with it.

**Dr. Szmuilowicz:**

Palliative care is a subspecialty of medicine that focuses on helping patients and their families live to the best of their abilities with a serious illness. So the focus of palliative care is on symptom management, on support for patients and their families and on planning. In many ways it's about trying to attend to, alleviate or prevent any form of suffering that somebody may have when they're coping with a serious illness.

**Andrew Schorr:**

Now, what illnesses certainly come into play with this? We're not talking about acute conditions, right?

**Dr. Szmuilowicz:**

No, although certainly many of the conditions that we see have acute exacerbations. But really any illness that is life-limiting, and so we think about patients with advanced lung diseases, advanced heart disease, cancer, and neurologic diseases like Lou Gehrig's disease. It's not limited to any particular illness, rather it's for patients who are facing and dealing with an illness that is life-limiting.

**Andrew Schorr:**

Now, this term "quality of life," you know seems to be a more general term. How would you define it? When somebody says, well, I want to improve my quality of life, or you say to them, we want to help you have the highest quality of life possible, what does that mean?

**Dr. Szmuilowicz:**

I think it's a very individual answer. I think for every patient, they have a different definition of what quality of life means to them. And I think the focus of palliative

care and the focus of the whole interdisciplinary team is to focus on those things that are affecting somebody's quality of life or focus on those things that are causing suffering in any of its dimensions, be they physical symptoms, psychosocial symptoms, coping with the illness or uncertainty about what lies ahead.

**Andrew Schorr:**

So pain of course might be part of it. Don, pain has not been your issue, right?

**Don:**

No.

**Andrew Schorr:**

Okay. But on the other hand, it could be anxiety, as Don mentioned, or it could be pain, or it could even be mental health issues. Those would all fit in with palliative care, right doctor?

**Dr. Szmilowicz:**

They all would. Anything that affects somebody, the way they are living life with their illness, and so most of the time--a lot of time we focus on pain, but in the asthma and COPD program where we work together, the most common symptom is shortness of breath. And we focus on that and work on different strategies, either with medications and often without medications to try to help people live with their shortness of breath as best as they can.

We also focus on nausea, constipation, fatigue, and difficulty sleeping. You mentioned anxiety and depression, and a lot of people may not necessarily have ever been diagnosed with anxiety or depression or a formal disorder, but because of their illness and because of the symptoms that they have, as Don mentioned, they're always worried about when the next time is going to come that they feel short of breath. Or they're isolated because of their symptoms and their declining function, and sometimes just talking about it and having a plan about how to deal with it is really helpful.

**Andrew Schorr:**

So Don has a device, or maybe a couple, Don, that help you with oxygen. I think you're on continuous flow now, so that's putting oxygen right in your nose to help you breathe better, and that allows you to go to the senior center and other places that are important to you, right, Don? Did I get it right?

**Don:**

Yes.

**Andrew Schorr:**

So, doctor, would that be one of the things that you do is you sit down with someone and you say, okay, you've got a serious lung disease, in this case, what's important to you? What do you really look forward to? Like for Don it's being independent, being able to go some places, go to the senior center, be a volunteer. And then you work maybe with other doctors as well and other team members to

see how you can make that possible while managing the illness. Is that the way to see it?

**Dr. Szmuiłowicz:**

That's exactly right. I work as part of the team in the Asthma-COPD program at Northwestern, and Don and I and Don's pulmonologist, we actually see each other on the same day. And Dr. Kalhan, who is Don's pulmonologist will come and see Don and review his medications, see if there's anything else that can be maximized in terms of his therapy for his lung disease. And I have the luxury of spending a little extra time with Don, seeing how that shortness of breath--how he's coping with the shortness of breath, and what that's like and how we can think about other strategies to help him maximize his energy use and focus on those things that are really important to him.

**Andrew Schorr:**

Now, this specialty you're in, palliative care, maybe it's been around for a long time but we haven't heard about it much, and I know I've read articles, it seems like this is more of an emphasis of medicine now as so many of us unfortunately have long-term chronic conditions.

**Dr. Szmuiłowicz:**

Yes, I think that's, that's exactly right. That's the focus of--I mean, to be honest, much of medicine is really about palliative care. It is about focusing on maximizing patients' function, about minimizing their symptoms, minimizing the burden of disease, and understanding that many of the chronic illnesses that we face today are not curable but they can be manageable.

**Andrew Schorr:**

Now, you mentioned a number of different conditions and unfortunately not only do we not have cures for some of these conditions but they tend to be progressive, even with the best medicines. So is that part of the discussions with people too, that they're on a journey, hopefully it's long-term, and how in being their partner in that journey they can have the best quality of life for each stage?

**Dr. Szmuiłowicz:**

I think that's exactly right. It's about finding the best amount of support for each patient and their family to be able to cope with that illness as they go through that journey and try to make every day as good as it can be.

### **Coordinating Palliative Care**

**Andrew Schorr:**

How does it work at Northwestern? So you gave the example in pulmonology, and you work with a pulmonologist. Now, there are other members of the team, and this comes into play in other illnesses too. So how does all this get coordinated?

**Dr. Szmuiłowicz:**

There are different ways that patients and families can access palliative care. If

patients are admitted to the hospital and they need to have inpatient treatment for their illnesses, they can request consultation with a palliative care team. Clinicians can also request that we come and help, again focusing on symptoms and support.

What we're developing now that is relatively new and growing is an outpatient program so that patients who are receiving care from their primary care physicians or clinicians or their specialists can also have access to palliative care, and our visits with patients are coordinated through the patient's primary care physician or primary specialist.

**Andrew Schorr:**

Let's talk about cancer, as I'm a cancer survivor. You know, so often the patient or the family say, 'well, we're going to fight this' and the doctors say it too, 'we're going to fight this,' and ideally of course you want to cure the cancer or knock it back into a long remission. But sometimes when this term "palliative" comes up one would think, well, I'm not a fighter anymore, I'm giving up. Maybe you could talk about that a little bit, about how we should see that while we're still trying to do as best we can against the disease that we have.

**Dr. Szmuiłowicz:**

Yeah. I think that's a common misconception about palliative care. I think that, you know, the focus on quality of life and treating suffering is applicable at any stage of a serious illness. And it's true that a lot of people feel like palliative care is reserved for the end stages of disease or when people are close to dying, but the truth is that people have symptoms, people are afraid, they're anxious even at the beginning of an illness journey, as you described it, and sometimes they benefit or want some extra support along the way. Or they need some extra special focus on symptoms or support that they need while they're going through their treatment. So there is no reason why patients can't get palliative care and aggressive attempts at curative care while they're addressing their illness.

**Andrew Schorr:**

Now, some aggressive care for treating an illness can have side effects, of course. So is part of what you do--you mentioned constipation and nausea and things like that--helping people deal with the side effects of the treatment so that they can do better and stay on the course of treatment?

**Dr. Szmuiłowicz:**

That's exactly right. That's exactly right. And there are many specialists at Northwestern and other medical centers who are very good at treating those symptoms, and sometimes they need some extra help or the family feels like they need some extra help, and that's where the addition of a palliative care team would be really helpful.

**Where We Are Now With Treatment Tools**

**Andrew Schorr:**

So where are we now with the range of tools that you have? I mean, obviously you have the wisdom, your skill, the other members of the team, but as far as different medicines or other approaches, medical devices perhaps, what other accommodations do you need to really make is dent in this?

**Dr. Szmuilowicz:**

Yeah, I think the key to understanding the range of tools is focusing on the multidisciplinary nature of the work. As a palliative care team we have physicians who have advanced training in symptom management and psychosocial support for patients with serious illness. Part of our team is nurse practitioners who have advanced training with similar types of issues. We have social workers. And we partner with the specialists—we partner with psychologists and psychiatrists who are trained to manage severe psychosocial illnesses or problems, anxiety or depression.

And then we also partner with complementary and alternative medicine providers who may also have a different way of treating somebody's symptoms or discomfort.

**Andrew Schorr:**

So it's not at all just a 'one size fits all' approach, where if you have pain we're going to give you this pain medication, end of story, or if you have depression or anxiety we're going to give you this pill, and that's it?

**Dr. Szmuilowicz:**

Correct. We have as part of our armamentarium, we have medicines, but we also try to understand where patients are coming from and try to understand what are the other options that may be helpful for them as they go through their treatments.

**Andrew Schorr:**

Now you mentioned complementary medicines. Recently I interviewed someone with more advanced multiple myeloma and cancer and so she has pain, and she's found in her case that acupuncture has helped. So that's something that might be part of a palliative care approach?

**Dr. Szmuilowicz:**

Absolutely.

**Andrew Schorr:**

Okay. So you're open to all of that.

**Dr. Szmuilowicz:**

We are open to all of that. I mean, I really think that, you know, in all of our discussions we talk about the pros and cons or the burdens and benefits of any treatment or procedure, and we discuss that. Because I truly believe that there is no one treatment for every patient, and we will do anything we can to try to find the treatment that maximizes the patient's quality of life and relief of suffering.

**Andrew Schorr:**

One thing that came up in Don's case--Don, so you've been living alone all of your adult years, right?

**Don:**

Well, not all. But yeah, recently.

**Andrew Schorr:**

Right. And so many, really millions of people in America live alone as adults, and then unfortunately they may have a serious illness. So, Doctor, that's part of the equation too, is what support do people have or are there social services that could be arranged to help them?

**Dr. Szmuilowicz:**

Yeah, I think that part of the reason why we work as part of a team is that we absolutely need our social work colleagues to help us identify resources for patients who need them, who need a little extra help in living in the community, living at home, or living in a nursing facility, that need a little extra support. Because most people want to be able to live as well as they can away from the hospital and away from medical settings, and your goal is to try to help them with that as best as we can.

**Andrew Schorr:**

Dr. Szmuilowicz, let's go on and talk about families for a minute because when we began the program and you defined palliative care you didn't just only talk about the person with the diagnosis but you talked about caregivers, and I would extend that to families. I know that we've had serious illness in our family—as I'm a leukemia survivor—and it affects everyone. So where does your discussion with the family come in?

**Dr. Szmuilowicz:**

So I think it starts with understanding that the focus of our care, like you said, is not just the patient but the entire family. We understand that when patients go through serious illness and they're dealing with serious illness it affects their loved ones in very profound ways. And some of the suffering that we try to address with patients is also being felt by their family members, so it's really about trying to provide as much support for everyone as we can.

So it really starts with trying to understand how patients and families are coping with the illness. We try to understand what life is like. We try to understand what kinds of effect the illness has had on the patient and their family in their day-to-day life, and we try to get a sense early on what's most important to the patient and to the family. And often we find that some patients have been very open in talking to their family about what their illness is like and how much support they need, and their family members or close caregivers are intimately involved in their care.

And other times, I think because people want to protect each other, there hasn't been as much conversation, and we sense that there is some fear, and that's totally understandable when you're dealing with a severe illness. So some of this is about

opening communication about where things are, what people are most concerned about, and what are the options going forward so that people have control over their care.

**Andrew Schorr:**

I'm just going to share a brief story here because I lived it. When I was diagnosed in 1996 through a routine blood test with chronic lymphocytic leukemia, you know, we didn't know what to make of it, and I thought I was dead, and I was 45 years old with little kids. And my wife tends to be anxious, and it really aggravated the anxiety for her. She was just a wreck. And so we went through counseling, and ultimately she did receive some medication that helped a lot—and that made things easier for me, too. She was feeling better and she had more equilibrium, and that also provided strength for me.

So do you look at that as a unit and say, okay, I want the patient to have the highest quality of life and I care about the family and I understand how these people interact, so you kind of look at it as a dynamic?

**Dr. Szmuiłowicz:**

Yes. You can't separate patients from the important people in their lives because not only are they crucial for the care that they're receiving but this illness, a serious illness, a life-limiting illness obviously affects everybody who is in the patient's sphere, and I think we have to do that if we're going to take the best care of the patient that we can.

**When to Start Palliative Care**

**Andrew Schorr:**

All right. Let's back up a little bit on how this starts. So I know you're a believer that palliative care can start early--

**Dr. Szmuiłowicz:**

Yes.

**Andrew Schorr:**

--in the course. So let's talk about some examples. If somebody is diagnosed with COPD or somebody is diagnosed with Lou Gehrig's disease or ALS, and we know unfortunately that these diseases tend to progress over, usually an extended time. So when does somebody say, 'well, can we get the palliative care team involved' and still feel like they're really still working on fighting the disease?

**Dr. Szmuiłowicz:**

Yeah, I think the question about when to get involved is a good question because I think it depends on what resources are available. I can think to the program that we have at the Northwestern Asthma-COPD program.

**Andrew Schorr:**

Sure.

**Dr. Szmuiłowicz:**

I work very closely with the pulmonologists and the nurses who are part of the clinic, and we have tried to come up with a way to identify patients who are suffering from their illness, either because their illness is very severe and their prognosis is totally unpredictable. That's a population of patients who may benefit from palliative care. There are patients who need extra help coping with their illness, either because of anxiety or fear due to uncertainty from their illness. That's another population. Then there's another population that are having severe symptoms.

So we try to identify the patients who are most likely to benefit or potentially benefit from palliative care. And the pulmonologists will in one of the routine appointments say, 'you know what, we're doing everything, we're going to continue doing everything we can to manage your illness, and we have as part of our program another member of the team who can help focus a little bit more on some of these other issues, maybe think about other ways to help treat your shortness of breath better or think about other ways to think about planning, advanced care planning when it comes to your illness so that you have control over what happens next.'

Or Don mentioned having somebody who spends a little extra time talking and trying to understand what it's like. They just need a little extra support, and I think that's a luxury to have when are fighting a chronic illness like COPD or any other chronic progressive illness. And none of it has to come with an admission that you stopped fighting; it's totally independent of the prognosis. The main thing is that it's a serious illness and recognizing that these patients may need a little extra support.

**Planning for the Future**

**Andrew Schorr:**

Now let's talk about planning for a minute.

**Dr. Szmuiłowicz:**

Yes.

**Andrew Schorr:**

So I think of living wills and durable powers of attorney, maybe even Do Not Resuscitate instructions, things like that. So--and we're all going to die someday. So how do you talk about this with people so that they feel more in control?

**Dr. Szmuiłowicz:**

Yeah, I think those conversations are all about giving patients control over their care, and I think that, you know, unfortunately those conversations were politicized and misrepresented a couple summers back, but I think ultimately this is about

understanding the illness, understanding where the illness is likely to head, and starting to plan in advance for what kind of care makes the most sense given what's most important to the patient. And it's about talking in the least threatening way possible about what's most important, and then how can we match the type of care to what's most important to the patient and to the family.

And it's really about giving the patient a voice. And what I talk to patients about is that we want to be able to respect your wishes about the care that you will receive. Again, whether it's at the end of your life or well before, we want to be able to respect your wishes. We also want to make sure that we all understand what to expect when it comes to this illness. And we want to know what kinds of things are really important to you when it comes to your care, what kinds of things would be totally unacceptable to you when it comes to your care. And that gives you a voice, and it also gives the family or whoever the decision makers are for the patient a gift in the sense that all they have to do is carry out the wishes of the patient because we've already had this conversation. It doesn't have to happen in an emergency setting. It happens hopefully well in advance when people have some time to think about it, to talk together, and really focus on what's most important.

**Andrew Schorr:**

Don, I'm willing to bet you and your doctor here, you have had conversations like that.

**Don:**

Oh, yes, yeah.

**Andrew Schorr:**

And this whole idea of doing it in a planning way and giving you control, that must make you feel more at peace doing that rather than there was some kind of emergency and a lot of things were being discussed in that setting.

**Don:**

Yes, it does. It gives me a little more confidence and makes me feel a little more secure. Because there's a lot of—you know, when you have a disease like this every day is different. You know, you can have a very good day, like today, but then I can't predict how tomorrow is going to be. It might not be very good at all because, you know, maybe the pollution is high or the pollen counts is high and it makes it harder to breathe, or I start coughing, you know. So one thing you need to learn I think at the stage that I have of COPD is just to take one day at a time and, you know, kind of just try to be mindful.

**Andrew Schorr:**

One of the things that we brought up earlier is the idea that accessing the palliative care team means that you're giving up. What would you say to people about that—because some people think that?

**Don:**

Well, yeah, that's not true at all. I think it's just the opposite. It encourages me.

It encourages me and inspires me to do more, to be more active. At the same time it helps me to understand that there are limits, you know, and I'm not going to live as long as maybe my sister, but, you know, that's understandable. I understood that when I was smoking. I knew that smoking was bad for me and it was killing me, but it's a serious addiction and I kept on smoking anyway.

**Andrew Schorr:**

I know. On other programs we've talked about the people who are able to quit, they may have tried 14, 15 times trying to do that. I know how hard it can be.

Doctor, so when you have a conversation with Don and your other patients and you begin to come up with a plan, how do you make sure that everybody knows the plan? Like for instance at the hospital, does it go in the chart? If you have an electronic medical record, does it go there? How does everybody get on the same page?

**Dr. Szmuiłowicz:**

I think that's a fantastic question because I think that's the eternal struggle. When we have a conversation, I think when we get to a point where everybody feels comfortable with our plan—but there again, the plan is not written in stone. It can change as many times as needed. But when we have a plan or we agree on what makes the most sense, we try to focus on identifying a power of attorney for healthcare so that again the patient has a voice if he or she can't speak for themselves in time of crisis or if their illness is progressing rapidly.

We fill out that paperwork, and if there's any other specific instructions that we've discussed that we all agree makes sense, then we write it down on that form. We also write a note in the chart, and we try to make sure that that is in the electronic medical record in multiple places so that if the patient gets admitted to the hospital that information will pop up and hopefully be very easily accessible to any care provider who is taking care of the patient.

And the other important thing is to also discuss with family members or patients themselves that we are available to them. So if things are not going well they can call us anytime. If they need to come into the hospital we want to be called so that we can be part of their care on the inpatient side as well as on the outpatient side. Again, trying to make sure that as best as possible, we all can understand and respect the patient's wishes for the kind of care that they want to have.

**Andrew Schorr:**

I want to switch to an illness different from Don's for a second—cancer—because some people living with some more advanced cancers, one of the big issues they have is pain.

**Dr. Szmuiłowicz:**

Yes.

**Andrew Schorr:**

Maybe the cancer has spread to their spine or bones, etc. And we were talking about perceptions a little while ago, and some people feel that 'well, if mom takes a heavy-duty pain medicine she's going to be a drug addict.'

**Dr. Szmuiłowicz:**

Yeah.

### **Treating Pain**

**Andrew Schorr:**

Let's talk about that as far as helping people feel comfortable so that they can do the best they can during that day and this whole concern about pain meds for a minute.

**Dr. Szmuiłowicz:**

Yeah. I think that concern about stronger pain medicine, opioids or narcotic pain medicines—those concerns are very common, and we hear that all the time. Fortunately, the risk of addictions with those pain medicines for people who are taking it because of acute or chronic pain, particularly when it comes to cancer pain, the risk of addiction is very, very low. And if people have never had problems with addiction in the past it's not something that I worry about.

And what we talk about is using the medicines to try to maximize function to the best of our ability. Our goal is often not to take the pain away entirely but to have the pain be at a level so that people can do the things that are important to them and things that they really need to do and things that they want to do. And it's an ongoing process where we work together. We try to adjust the levels of the pain medicine, again trying to get the lowest dose that we can to achieve the maximum function.

And there are other ways that we can help people treat their pain that don't involve narcotic medications, and to the best of our ability if we can employ those other modalities we do that too.

**Andrew Schorr:**

Yeah, like we were talking about acupuncture before. And for some people, it may be counseling.

**Dr. Szmuiłowicz:**

Exactly. For some people, it's biofeedback, and for other people it's counseling, it's learning to cope with their pain, it's strategies for minimizing their pain when they do certain things. Some people benefit from radiation therapy, for example. In the case of cancer, if there's a solid tumor that's causing pain sometimes radiation helps. Sometimes there are interventional procedures like numbing medications that we can instill in the site with a needle. There are also physical therapy modalities. There are lots of different things that we try to do. And there are nonnarcotic medications that we try, again, to try to achieve the best possible pain

relief with the best possible function with the lowest amount of medication.

**Andrew Schorr:**

It sounds like the word we're trying to get at and trying to have people not have in their vocabulary is "suffering."

**Dr. Szmuilowicz:**

Yes. As best as we can, we want to try to—though sometimes we can't fix the underlying problem, and sometimes we can't take away everybody's suffering, but sometimes just having somebody or having a team, be it social workers, nurses, chaplains, physicians, who can sit with patients in their suffering and be present with them in their suffering is helpful. To know that you have somebody along the way in your journey as you're dealing with this illness is really helpful.

**Andrew Schorr:**

I can certainly see that. Don, you have mentioned to me that attitude is so important. So talk about that for a minute, how you think of attitude making a difference.

**Don:**

Well, I think living in the present, you know, being mindful, is the best attitude. You know, what can interfere and make things worse is sometimes you can drift subconsciously into kind of a dark place, and memories sometimes, you know, can make you feel like not being very active. Every morning when I get up I have to deal with these memories, and I have to push myself a little bit to get on and become active. And I don't know but it seems like I'm enjoying life more now than I did before I had this disease.

**Andrew Schorr:**

Wow. And the palliative care team has helped?

**Don:**

Yes, yeah. They have helped reinforce that belief, I think, and I think that's very good. So far I've had a pretty good attitude—except for this anxiety I had last winter and this spring, but that seems to have gone away now, so.

**Andrew Schorr:**

That's great, and that came out of your discussion with Dr. Szmuilowicz?

**Don:**

Well, it helped a lot, yeah. I don't know to what degree the anxiety subsided because of the palliative care discussions, but I'm sure it had a significant effect on it.

**Andrew Schorr:**

Doctor, let's understand the role of the different members of the team. So of course Don has a pulmonologist and maybe has other specialists as well and depending on which condition somebody may have a neurologist or an oncologist,

cardiologist. So they don't give up that doctor. Palliative care is additive. Am I right?

**Dr. Szmilowicz:**

That's correct. That's correct. So in Don's case I work very closely with his pulmonologist and with his primary care doctor. And he continues to see them, and we all work collaboratively to try to do everything we can to help Don live as well as he can. I think all our goals are aligned, and Don continues to see all of his doctors and benefit from their care irrespective of my involvement. It is really additive and concurrent with their care.

**Andrew Schorr:**

Now, I used this term earlier that we're on a journey when we have a serious illness. We're on the journey of life, but it may be overlaid with a serious diagnosis, COPD or an advanced cancer or ALS, congestive heart failure, some of the conditions we've been discussing here, and we see that it's progressing, and we've done discussions and planning and maintained quality of life and adjusted that along the way, but at some point it may be clear that we're nearing the end of life. And I know palliative care comes into play there, too. I think certainly of hospice maybe at some point. Talk a little bit about that and where that comes in and how somebody can prepare for that. It's really been part of the discussion all along that we understood that life is a terminal condition for all of us.

**The Role of Hospice**

**Dr. Szmilowicz:**

So I think of hospice as being palliative care for the last stage of life. And the beautiful thing about hospice, when patients and families are ready for it, is that it is a total comprehensive team approach to caring for the patient and the family, doing the same kinds of things that we do in palliative care, specifically focusing on symptoms, focusing on psychosocial support, doing ongoing planning, providing services at home or wherever the patient may live, providing extra support for the family and providing support for the family even after the patient dies.

And I think it is again another layer of support. It is a tremendous layer of support for patients and families when they've gotten to the point where they understood that the treatments are no longer benefitting. The treatments to try to cure or control the disease are no longer necessarily benefitting, and they want to focus on aggressive symptom management, and they want to focus on being at home or being out of the hospital or some of the life closure events that are really important for people to do before the end of life.

**Andrew Schorr:**

You know, one of the things I wanted to discuss goes back to I know a favorite topic that you have, and that is communication. So I see the communication that you have with patients, these discussions Don has with you, your other patients, the planning you do. We're in a world now where family members may be

dispersed, and ultimately someone with one of these conditions may be in intensive care or be in hospice, but in some situations like that, somebody flies in from who knows where, and they think things should be different.

**Dr. Szmuilowicz:**

Sure.

**Andrew Schorr:**

And I know that's very uncomfortable for everybody. How do we head off some of those situations so that it can be more peaceful and a more positive thing.

**Dr. Szmuilowicz:**

You know, I don't know if it's possible to head off every time, but you're right, those are difficult scenarios and difficult situations. And I think we all understood that when people are far away and they haven't necessarily seen the changes day-to-day, this is a huge shock, and it's an emotional roller coaster for them, and it's over a very short period of time. And I think we all as providers try to understand that this is really difficult for the family members or the loved ones who are coming in.

And I think, you know, some of the things we try to do to head this off is to talk about it this early on so that people are as prepared and aware of what's happening as possible and that they can be as involved in the patient's care as the patient wants them to be and as comfortable as they want—as comfortable as they feel being. But I agree. I think we underestimate how important this open communication is, and we underestimate how important it is to happen early.

All these things are a process, and I think we all need time to understand what's going on, to get used to what's going on, and to deal with all of the emotions that have to do with illness and the threat of losing a loved one.

### **Is Palliative Care Right for You?**

**Andrew Schorr:**

Well said. Well said. Don, you've been listening and you know that we have folks who are accessing this program who are just learning about palliative care for the first time and are wondering would it be right for them, and maybe they're a little hesitant or feeling that it means they're giving up, which we clearly understand now that's not the case. What would you say to them about considering taking advantage of it?

**Don:**

Well, I think that they should try it and, you know, I think that they're going to find out that their worries about it are unfounded. I think that they'll find that it's to their benefit and, you know, I think that after talking to a palliative care specialist they'll feel a little more confident and more in control of their situation.

**Andrew Schorr:**

Don, how do you feel about the future? So you have oxygen 24 hours a day to help you, but you're still doing a lot of activities that are important to you. How do you think of the future? Or is it just that today is a good day and you celebrate that?

**Don:**

Well, yeah, that's true, but sometimes, you know, you can't help but think about death, you know, and what lies beyond death. But I'm not concerned so much about that. I mean, when I first went to the hospital with this disease I almost slipped away, you know, and I know how easy that can happen. So I don't know, I'm not afraid of it. What will be, will be, you know? I enjoy today, and maybe overnight I'll die, and I really don't care that much. I mean, you know, I want to stay healthy. I'm not trying to die and I have things that I want to do, but that time will come and when it comes it will come, that's all.

**Andrew Schorr:**

Wow. That sounds like a very healthy attitude for sure, and I know you make a difference for people as you go to the senior center and volunteer, and you're making a difference for people just talking about it here. Don Lartz, I want to wish you the best on your journey, and I want to thank you for being with us.

Doctor, I want to just get some final comments from you. So just to sum of up, it sounds like with palliative care it is—to me sounds like a wonderful service in addition to those medical folks who may be helping us fight the specifics of our illness in enhancing our quality of life and making, if we can, making every day special.

**Dr. Szmuiłowicz:**

That's exactly right. And again, I want to thank Don for the way he described it, and I think it's about quality of life, as you talked about, and it's about having some more control over the day to day wherever we can dealing with diseases where, to be frank, we don't have a lot of control over them. So it's really about giving patients and their loved ones some control over what happens next, and it's about making every day as well as good as it can be. And when we get to that point at the end of life it's about making that last stage of life and the dying process as comfortable and as dignified as it possibly can be.

**Andrew Schorr:**

Yes. It should be that way. I want to mention, just stress something that we've talked about throughout, and that is communications. So it is your right as a patient or a family member supporting a patient to ask if palliative care is available. It certainly is at Northwestern Memorial Hospital, and for outpatient as the doctor talked about as well, and then take advantage of that, have that integrated into your team. You're not giving up the primary doctors who are supporting and fighting the illness, but it's additional, and as you can hear, it's a wonderful addition.

And then, Doctor, I think you'd agree that quality of life issues or symptoms that

come up, they may change over time and so there's always that dialogue of what's going on. Could be pain, could be anxiety, could be complications from some aggressive treatment, and that's what's on the table to discuss.

**Dr. Szmuilowicz:**

That's exactly right. Things change over time, and I think as Don said, we want to be as present in the moment as we can, trying to deal with as much as we can in the moment, be they symptoms or anxiety or stress or fear, and also help to plan for what may come next and give people control that way too.

**Closing Comments**

**Andrew Schorr:**

Dr. Eytan Szmuilowicz, thanks for being with us. Thanks for your dedication to patients and their quality of life and the whole team you represent at Northwestern Memorial and your specialty nationwide. It's such a contribution to us as we fight serious illness. Thank you for being with us, sir.

**Dr. Szmuilowicz:**

Thank you for having me.

**Andrew Schorr:**

And, Don, all the best, okay?

**Don:**

Well, thank you very much.

**Andrew Schorr:**

Thank you. I hope we'll get to talk again and you'll tell me more stories of living in Chicago and also your volunteer work and the great, great things that you do.

This is the kind of discussion we have time after time on our programs that are seen in the ihealth area of nmh.org and that we produce here at Patient Power. And I want to urge you to take advantage of the whole library of programs but also tell others about this program on palliative care because it touches people with so many illnesses and needs to be recognized more as a service that can be brought to bear.

I'm Andrew Schorr. Thanks for listening. Remember, knowledge can be the best medicine of all.

*Please remember the opinions expressed on Patient Power are not necessarily the views of Northwestern Memorial Hospital, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.*