

**[00:00:00] Bonni Stachowiak:** Today, on episode number 344 of The Teaching in Higher Ed Podcast, Sharon Hamill joins me to talk about Caring for the Whole Person.

**[00:00:12] Production Credit:** Produced by Innovate Learning, maximizing human potential.

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**[00:00:21] Bonni:** Welcome to this episode of Teaching in Higher Ed. I'm Bonni Stachowiak and this is the space where we explore the art and science of being more effective at facilitating learning. We also share ways to improve our productivity approaches so we can have more peace in our lives and be even more present for our students. Sharon Hamill, PhD Psychology Professor at Cal State University San Marcos is recognized for her leadership and palliative care education and innovative approach to raising awareness about completing advanced directives for healthcare.

As founding director of the CSU Shiley Institute for Palliative Care at Cal State University, San Marcos, Hamill created and continues to direct the What Gives Your Life Meaning, WGYLM, annual campaign. Held over the last five years, the campaign raises awareness for students, staff, and faculty to advocate for their own healthcare, including planning for advanced directives.

The campaign features guest speakers, a resource fair, films, and discussion panels, and a pledge drive to increase the number of students completing advanced

directives. WGYLM allows students to take leadership in educating the community. For example, students developed a website to support children and young adults who serve as family caregivers and lead workshops on palliative care. Sharon, welcome to Teaching in Higher Ed.

**[00:02:08] Sharon Hamill:** Thank you. It's wonderful to be here.

**[00:02:10] Bonni:** I am excited to get to hear about your work. I'm just having this sense that so many of us are going to get so many benefits from today's conversation. Thanks for joining me on this day, and especially during this time.

**[00:02:25] Sharon:** Oh, I'm so delighted to be here. I think here are some really wonderful messages to share.

**[00:02:29] Bonni:** Talk to me about where you first remember hearing about palliative care.

**[00:02:36] Sharon:** It actually happened when I was pregnant with my third son and I was diagnosed with melanoma. I went into a doctor's office and I heard them refer to me as the pregnant melanoma patient. I was so devastated by that, that I was not a human being that I was a disease. I started to do some investigation into this topic of how do we deal with people with disease.

I'm an expert in family caregiving. Really, it grew from there. Then when the CSU Shiley Institute for Palliative Care was established at Cal State San Marcos, I jumped at the opportunity to be the Faculty Director, because it meant that I would be able to use my research and to help contribute to a world in healthcare that would recognize people, not diseases.

**[00:03:38] Bonni:** I know our conversation today is going to blend our teaching in with our personal lives which, of course, isn't that really how it works anyway.

**[00:03:46] Sharon:** Absolutely. It's funny because especially working on a college campus and palliative care, we often got questions like why would you be teaching about this to these young people? My answer was always, "Why wouldn't we?" We need to make this as much a part of our life as anything that has to do

with healthcare or major life events. We know that college students daily are dealing with illness and death. We may not see it, we may not hear about it until there's a funeral and the student needs to take some time off.

The truth is, we know from a recent AARP study that about 11% of college students, that's about 5 million college students, are actually caregivers in their families. This is something that they're living with daily, but they may not tell us. We may see it in an absence. We may see it in a failure to complete an assignment but the truth is, these students are trying to navigate some very difficult roles simultaneously and they often do it alone.

**[00:05:00] Bonni:** It's been an interesting semester for me in terms of the ways in which having more asynchronous online assignments have allowed me to see some of these glimpses. Now the class I have been teaching as a class about personal productivity but just like us talking about our lives as both teachers but also, there's so many other aspects to our lives, of course, the same thing would be true for our students. Just to be able to see me talk about major life events, the number of students losing parents, and dealing with their own COVID diagnoses or family members.

It seems bigger than ever before. Some of that, of course, has to be true but some of it's always been there, and I just didn't have as many glimpses into it. Would you talk about, for your own experience in your teaching, was there a time when you started to be able to see more of these glimpses of your student's lives, like the things that maybe you would have just counted as an absence before and then times now where you're able to see more of that?

**[00:06:08] Sharon:** Absolutely. I think the pandemic has really laid open for us to see things that have been there for a very long time. Because we haven't given a name to it, or we haven't recognized the responsibilities that our students have or the responsibilities that faculty, staff, and administrators have too, it's almost as if we treat that work environment in that school environment as somehow being unaffected by things going on in the outside world.

The pandemic has made that painfully clear that we aren't immune, that we are impacted by what's going on in the outside world. What it has done-- I always try to look for silver linings but I see that it has made us all much more cognizant of those family responsibilities that our students have, that our faculty have, and really, anybody connected with university. Then it becomes like when you talk about the asynchronous classes, we know that these young caregivers, these college student caregivers, are more likely to take those kinds of classes because they afford them the opportunity to manage their family life while they're still trying to get that college education.

I think we are really opening our eyes to it's not just a student trying to combine work and school, but there are some very real family responsibilities that are impacting their ability to do either of those roles. How are we responding in a way that still provides access and equity, and really gives them the opportunity to be socially mobile and get that college degree?

I think it is a shift that we're going to see ongoing, now that our eyes have been open to this. It's not just when a student comes to you and says, "Hey, I have an ... I can't come to class," maybe we're going to think a little more deeply about why is that that the student is doing that. I think that's the beginning of some great changes.

**[00:08:26] Bonni:** How do you explain to people what palliative care is and also, what it's not?

**[00:08:32] Sharon:** Oh, this is a great question because I actually spent a number of years on a board of a hospice. When most people hear palliative care, they connect it to hospice, because hospice services, which are focused on those people who are terminally ill and expected to die within six months, they get palliative services. We think of palliative care as an extra layer of support. It's typically offered in palliative care teams. You might have a physician, a social worker, a palliative care nurse, a chaplain.

The idea is that rather than just focusing on the disease state of that individual that's saying, "Let's look at the whole individual, and what might they need," and maybe they need some chemotherapy or they need some physical support. Most likely, they also need emotional support, a support with their family relationships, and spiritual support. Traditionally, palliative care has been found within hospice. Often when I would speak to people about palliative care, they assumed I was telling them, "You're likely to die within six months."

A lot of education around, "No, we're talking about why should you have to be dying to get whole-person healthcare? Why should you have to be terminally ill to get the support that all of us benefit from when we get treated as more than our disease state?" A lot of the education around palliative care is getting people to understand that this is about supporting the whole person who happens to have a serious illness that may or may not result in the end of their life but they're worthy of support. What can we do to help make that journey they're on more palatable for them and for their families, and actually increase their quality of life?

**[00:10:38] Bonni:** Would you tell us about your work with What Gives Your Life Meaning?

**[00:10:44] Sharon:** This has been just one of the best projects I've ever had the pleasure of working on. About four or five years ago, there was a faculty learning community that came together to focus on palliative care. We said, "What could we do? What kind of project could we do for our students that would help educate them about palliative care?" We were actually told that we were crazy for focusing on students because they know they don't want to talk about those things. The truth is, they do want to talk about those things. They need to talk about those things.

We established a series of events that would focus not on death and illness, but on the positive side, what gives your life meaning, and who needs to know. We began by putting signs up all over campus that had the letters WGYLM, and didn't say what it was referring to, which created a lot of interest and questions about what is this. Then at a couple of weeks later, we laid out yard signs, like the old Burma shave signs so that as they were walking across campus, they saw these signs that

said, "What gives your life meaning?" Then the last one was and who needs to know?

Then the campus conversation became about what was important to people. This created an opportunity for us to introduce the idea of advanced directives and say, "These are all important things to you that make your life special. Have you shared this with people that are close to you?" If there was a time in your life where you couldn't speak for yourself, would they know what to do and what was important to you? It was really about conversations. We included things like a pledge drive, asking our students to pledge to have a conversation because I believe completing an advanced directive is a process.

Rarely does a person sit down and decide to say what they're going to put in their advanced directive, which is really a legal document that instructs your physician as to what your wishes are, and who you would like to speak for you in the event that you cannot speak for yourself. We talked with students about, have they ever had this conversation with anyone? I always remember one student when we were talking about who would you want speak for you? She raised her hand and she said, "It absolutely would not be my mother."

I said, "Well, why not?" She says, "Because that woman would keep me hooked up to machines for 30 years. If this happened to me, I would need my dad to make those decisions." Then I asked her, "Have you talked with your mom and dad about this?" She said, "No." I really believe that so many of these students went home afterwards and talk not only for themselves but also asked that theory question. We asked them, "Do you know what your parents want?"

The whole idea was not to answer the questions for them but to get them to have the conversations because we believe that's how you can set up your life the way you want it to be but also in the event that there's a terrible illness or an accident, or a pandemic, that you're not left wondering, what would this person have wanted, that you've had the conversation and you each know what you're bringing to it.

**[00:14:35] Bonni:** We were introduced to advanced directives, although they actually the name has changed over the years. Actually at our church and my mom came up to the events that they would do I believe it was the associations Orange County Alzheimer's Association, or I'm trying to remember exactly the name of it. I'll find it and put it in the show notes. I've found for myself in my life that the first couple of times it was nice if there was another group that could facilitate or prepare you to have it.

Then it's been exercise over time in the sense of that if we don't let it go for too long, and just bring up these conversations, and of course, Alzheimer's runs in my family. It's really hard to have conversations because it's scary, but I had so much would rather just work through my own fear so that I do know the answers to those kinds of questions but it's really hard work.

I feel like in some ways, I've already been able to grieve the loss of a parent role because over your lifespan, your parent, then is no longer taking all those parenting roles on and eventually, if people live a long, great life, then eventually they do become a little bit more childlike in terms of needing more care from you. Some people as you already well know, that gets accelerated so much. Then you do see people in their 20s, that are having to take on more parental type of characteristics. That's a huge grieving process, in addition to just needing to have these conversations.

**[00:16:07] Sharon:** It's a very huge grieving process and it's also important that even though the roles you may take on more of making decisions for a parent, for example, there's still that dimension that they aren't children, or with children, we know as they develop, they will advance and get more skills. In the case of something like Alzheimer's, we know that we're looking at the ... It's a very complicated kind of process.

Your point about when do you talk about this, it is true that if a family member has a disease, that you may end up coming in contact with the Alzheimer's Association, or the Parkinson's Association. They'll get you thinking about it. If you're doing any estate planning, they'll get you thinking about it. With What Gives Your life Meaning,

our focus has been kitchen table conversations. You got a holiday coming up and especially if no one is ill. That is actually the best time to have the conversation because you don't have the anxiety of I need to make a decision today or tomorrow but just here's what's really important to me.

If I was at the end of my life, this is how I would want it to go. What would you want? Doing this over a cup of coffee and some pie and talking. Actually, I've three sons. My husband and I have had multiple conversations like this with them. I'll tell you that anxiety that you mentioned, we all have it, that I always tell the students in my own family that it's far easier to have some of that anxiety around that kitchen table than to be in a hospital ICU when someone's been intubated and trying to figure out what do we do now.

We're trying to avoid those situations, by having people contemplate this recorded in an advanced directive, which the State of California has a form that you don't need a notary. You can just fill it out yourself, have a witness sign it, and then make sure your doctor has a copy of it. Also, the person that you've asked to speak for you, you need to talk to that person and say, "Hey, I'd really like to put you down as the person who's going to be speaking for me."

Then like the student I was talking about, if there are people who think they're going to be picked as sure person, and they're not, you really need to have a conversation with them as well and say, "Here's why I picked the person that I did." The best possible time to do this is when you don't need to because there's an emergency that you're dealing with.

**[00:18:58] Bonni:** Tell us about your work with the youth resilience project?

**[00:19:03] Sharon:** Well, we know, based on a study that was done in 2005, at that point, they were telling us we had about 1.4 million caregivers under the age of 18. What we know is that is a gross underestimate. We know that the college students that we're seeing, the 5 million, most of them report that they were caregiving before they came to college. We have this hidden generation also referred to as



the forgotten generation of caregivers under the age of 18, who are managing roles that are typically reserved for adults.

They may be taking care of a parent or grandparent that's typically who it is or a sibling who's disabled. They may be doing some basic like housework and meal preparation, things like that, we call this instrumental activities of daily living. We found that a good number of them are actually doing the more intimate kinds of care for the activities of daily living, including things like toileting, and bathing.

When you are under 18, and you're doing these things, there's this very strange dimension, and this occurs across the globe, we look at caregivers in other countries as well. There is a fear that those under 18 have that if they let somebody know that they are providing care, the Child Protective Services will come in and take them away, which is not the case. They do fear that and so they don't tell anyone, and that means they miss out on opportunities to get support to help them and their families function.

The Youth Resiliency Project has different kinds of programs where we've worked in the schools, training care counselors in resiliency skills such as mindfulness, and using problem-solving techniques so they could share them with other peers at the high school to help build those resiliency skills for those young caregivers, and actually, any student who's dealing with any kind of challenge. We also had on campus, had retreats where we bring in students from the local schools, and we have the youth caregivers website on our campus website that provides some resources for those young people.

**[00:21:34] Bonni:** I'm trying to picture what this work might be like, and I'm thinking that it's possible there's a connection also with normalizing things, because then if I'm in these retreats, and I'm participating, then I see, oh, there's other people who also have to provide this care and struggle with some of the same things that I do. Is that true?

**[00:21:56] Sharon:** Absolutely, and that is one of the big things that we're trying to promote, is getting people to acknowledge there are millions of caregivers out

there, some identified many not, and the young ones are the ones who are being missed. What we can do is create materials for educators. For example, we have the K through 12, teacher counselor, workbook, or toolkit that provides information about young caregivers and grieving youth.

We have the What Gives Your Life Meaning manual, and both of these are free manuals that are available on the website that I'll talk about in a little bit, but the manuals are there to help people understand what is at their fingertips they can be doing when they're talking with a young caregiver when they're dealing with a bereaved youth, when they're trying to help a college student understand, you're not the only one. There are millions of us out there, you've got support, and here are the places where you can go to get the kinds of support that you need.

**[00:23:05] Bonni:** Before we get to the recommendations segment, I just wanted to hear a little bit about the work that students do with the St. Francis Soup Kitchen. Could you talk about that work?

**[00:23:16] Sharon:** Yes, you know what? That has been absolutely one of my greatest joys, unfortunately, right now with the pandemic, the soup kitchen has been shut down. What happened was I had a couple of Master's in Public Health graduate students who needed a placement so they could do an internship. They came to me and said, "I've looked at your St. Francis Soup Kitchen, one of the ideas was that we wanted to introduce the diners there to advance directives. We know that with homeless and low income, they often end up in hospital ERs, and nobody knows who they are.

They don't know how to contact family members. We wanted to bring in students who could help educate the diners about the services available in the community, and also the need for advanced directives." I had a couple of absolutely amazing women who came in and arranged for shot clinics and did one-on-one education, we often brought in supplies like toothpaste, et cetera.

They would come and talk with us, and it was an opportunity for these outstanding graduate students from Cal State San Marcos to be able to be on the front lines

actually educating folks about their own healthcare and things they could do to ensure they have quality of life. You often learn much more from your students than you teach them and watching them interacted, it truly was one of the greatest joys of my career to see them dive right in, get right in there with the people and do what they can to educate them so that these diners could make better choices for themselves with their healthcare.

**[00:25:15] Bonni:** I'm reflecting back on all of the stories that you've shared in our short time together, and one thing that hasn't come up yet, but I suspect it's just because I haven't asked [laughs]. That you're willing to embrace messiness, you have to be in order to learn from your students, as you just described now, and in order to make these opportunities available, would you just share a little bit about messiness, and then we'll each share our recommendations.

**[00:25:39] Sharon:** It's funny, I think, sometimes as educators, we think we have to have control over things and certainly, when you're out there, even on the campus doing a What Gives Your Life Meaning campaign where you have the students working with you to do the education at the resource fair, et cetera, or you're in the soup kitchen, and on any given Monday night, you never knew what you were going to get at the soup kitchen. To watch how quickly students could adapt based on what was being put before them, and I think for myself, it just hung my own skills that I have my plan, and then there's what actually happens.

We like to think sometimes as educators we have to have all the answers, but there's such richness to being in the trenches and having to really collaborate and problem solve with your students as things are coming up. Case in point, trying to get people to get flu shots and hepatitis shots at the soup kitchen and listening to people say these shots will give me those diseases, and then watching these public health students get in there and do their thing. I was just in awe. I think you have to embrace the messiness and recognize that that's probably where the best learning is going to occur.

**[00:27:11] Bonni:** I love that you tied it to control because it couldn't be more true, and not to mention, when I think back to my own life of my own resiliency, that as it

ebbs and flows, how do you ever gain resiliency in your life? Well, you've dealt with a lot of messiness, and you have. How could you get more resiliency skills if you weren't dealing with that?

**[00:27:31] Sharon:** Well, I teach a class on risk and resiliency, and one of the key things about resiliency is you can't be resilient unless you've had adversity.

Resilience is the ability to meet and overcome adversity so that adversity is a keen teacher, and we know, looking across and when we start looking at things like adverse childhood experiences, we know young people have these experiences that will impact their mental and physical health for the rest of their lives. It's in our best interest to say, what do we have? What do we know that helps to interrupt that?

One of the things that I always share with my students is that having an adult, a caring adult, in a person's life, whether it's a teacher, a parent, a neighbor, you actually have the ability to disrupt those negative outcomes. I think that gives that comes back to control, there are certain things you can control in a really messy situation, and that is being that solid rock, admitting you don't know all the answers, but hey, we're going to hang in this together, we're going to figure it out. Those lessons are golden.

**[00:28:49] Bonni:** This is the time in the show where we each get to share our recommendations, and I am cracking up so bad, Sharon, because I thought that my recommendation wasn't going to map to anything that you just said, but I actually just found a connection I'm pretty happy with right now. Speaking of control, as the pandemic emerged, I think many of us with some semblance of self-awareness would realize life felt very out of control. For me, sometimes this is not always the case, I have different ways that I might try to, and hopefully healthy ways, self medicate [laughs] and things like that.

One of the things that I discovered was just how good it feels to organize a drawer. It's not like I have the energy or the time to do massive projects, but I find a little bit of peace of like just taking a little thing and making it a little bit less chaotic in this

tiny little space that I can actually control and it doesn't bother anyone else other than [laughs] things are a little bit more organized.

I really got a big kick out of this television show on Netflix called The Home Edit and it is just your classic organizing show. They will often have a celebrity for the first half or second half of the show who they get to show their home and they have some fancy costumes from all their times on the show the office and how they organize their memorabilia around the show that they were on or it might be a member of the community that someone has nominated who's worthy of being served in this way.

It was really fun. There's that home edit, show and then there's also the home edit book. The book is, I tend to mostly just read digital books this way but this is one that I really wanted to be able to hold in my hand because of all the beautiful images inside of it. I would recommend both the home edit show on Netflix and also the home edit book. Sharon, I'm going to pass it over to you for your recommendations.

**[00:30:47] Sharon:** I think the first recommendation I would make to the teachers out there would be to go to [www.wgylm.org](http://www.wgylm.org), which is What Gives Your Life Meaning site. You can get a free manual that tells you how can you have this positive campaign or series of events on your own campus. It was written by faculty who are used to working with no dollars. It's very creative. What did we do to put it together and we said we wanted to share it with others so you can get that, other teachers out there that are working with young people that are grieving, or they're dealing with a family illness. There's another free the toolkit, the K through 12, teacher counselor toolkit to give you some understanding there.

Then I would also recommend that it's not a particular website because there's so many. The whole notion of mindfulness. Bonni, we've talked about the importance of breathing, and the importance of slowing things down. I think the combination of doing something to take a little control back over whatever it is, maybe it's you're going to have dinner set at a particular time at night and that's going to be your goal for the day. That gives you control, but also to recognize and acknowledge that this pandemic, the normal course of working with students and teaching and

living your life, there's constantly challenges being faced, learning how to calm yourself. They're wonderful, wonderful websites.

Cal State San Marcos has a mindfulness Cal State San Marcos, UCLA, UCSD. There are so many free resources out there that can help you learn how to calm yourself. The neat thing about it is a lot of educators from kindergarten up through advanced degrees are using these techniques with students because you can actually improve health. It's free. It's readily available. A good search on mindfulness will bring up all kinds of things for you to use and practice. I really do highly recommend it, especially right now.

**[00:33:17] Bonni:** I am so glad that the Cal State University system has connected the two of us. I've so enjoyed learning from you. I look forward to staying connected and being able to continue doing that and do my own search on mindfulness and see what pops up. Thank you so much.

**[00:33:32] Sharon:** That's great and thank you so much. It is so wonderful to get the opportunity to just share about teaching and I just love learning about what others are doing. Thank you so much, Bonni for what you do, too. You're doing a real service to all of us.

**[00:33:47] Bonni:** I appreciate it. It brings me joy. We're having this conversation in the morning time and you're just starting my day out, right. I feel like I'm in a more peaceful place. I really appreciate your time.

**[00:33:57] Sharon:** Great. I do as well.

[music]

**[00:34:02] Bonni:** What a pleasure it is to have been connected with Sharon Hamill and to get to have this conversation about the importance of advanced directives, and the whole idea behind What Gives Your Life Meaning and who needs to know about it. Thanks to all of you for listening as well. It's Episode 344 and I'm so glad to have you listening during this time.

Thanks for being a part of the community. If you'd like to receive our updates occasionally these days, please head on over to [teachinginhighered.com/subscribe](https://teachinginhighered.com/subscribe). Thanks for listening. I hope you'll share one of your memorable episodes with a friend this week. Thanks again. See you soon.

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**[00:35:02] [END OF AUDIO]**

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