



Healing from the Trauma of Having a Chronic Illness

Guest: Patricia Fennell

Niki Gratrix Hello, everyone! This is Niki Gratrix, your host. Welcome. I'm very excited, privileged, and honored to introduce you to a researcher and a clinician, who I believe is doing really important pioneering work on better understanding the physical, psychological, and cultural aspects of chronic complex illness. It's Patricia Fennell.

Patricia is a researcher, clinician, and author specializing in chronic illness, trauma, forensics, hospice, and global healthcare concerns. As the author of the validated Fennell Four-Phase Treatment Model (FFPT) and the president and CEO of Albany Health Management Associates, she lectures to advisors and consults with government, professional, medical, academic, management, and patient organizations in North America, Europe, Africa, and Australia.

Patricia has authored or edited several books on chronic illness, including *Managing Chronic Illness Using the Four-Phase Treatment Approach* and the *Handbook of Chronic Fatigue Syndrome*. She has also written numerous scholarly and lay press articles and chapters on the topic, including "Chronic Illness" for Oxford Bibliographies Online with Oxford Press and the "Chronic Illness" chapter in the *Oxford Encyclopedia of Social Work* co-published by Oxford University Press and the National Association of Social Workers.

A popular speaker, Patricia presents worldwide to medical, education, and criminal justice communities at conferences and meetings for both professionals and patients. And she continues to see patients; train and supervise physicians, nurses, and social workers; and administer a two-year training program in the FFPT model utilizing original content and curriculum.

So, Patricia, a very warm welcome to the summit today! I'm very excited to interview you. And thank you very much for sharing your time with us today!

Patricia Fennell Glad to be here, Niki!

Niki Gratrix So I'm really excited about the Fennell Four-Phase Model of Illness, which I honestly think every single practitioner working with any chronic complex illness should be aware of, but certainly with chronic fatigue syndrome, ME, and related illnesses. And I think it's going to be of great use for patients to hear this model, as well.

So I just wanted to start by asking you, Patricia, how the model came about. And where did it come from? How did you come up with it?

Patricia Fennell Well, it comes from two places, Niki. One, I have been diagnosed with chronic disease since I was a kid. Initially, I was diagnosed with lupus. So it was something that I had to live with and continue to manage my whole life. And many years later,

when I was a young worker in the Hospice Movement, I had the great good fortune to work during the Elizabeth Kubler-Ross years here in the United States. And she came and trained and worked in our hospice.

And I started the model there, in part, because her death-dying model was so elegant. But in her model two things had to be true. One, someone had to die. That's how it ended. And it really only addressed a very specific area of the chronic experience of suffering. At the same time I worked in hospice, I was starting to see patients and being asked to consult on complex cases: autoimmune cases, allergy, all kinds of things. And the model began to evolve. And part of it came from a few different places.

I realized that we really had to look not only at the physical aspects of what people were experiencing in their families, but also at what they were experiencing psychologically, some might also say spiritually. And what they were also experiencing socially. What was going on from a systems perspective for them and their families? And part of the ethos I brought to that was my training and experience in hospice, which was wonderful. And my thinking was, "if we could treat the dying this well, why couldn't we treat the living this well?"

So I really re-charted my course and began to think about how we carry people forward, help them with their lives, as they're living ongoingly with chronic disease. There was beginning to be some information out there about how to cope physically, though, it was not a lot. This was many years ago. But at the end of the day, people had to go home, either to go alone or to their friends and their families – however they defined family. And they had to live day-to-day. So that was part of the impetus for me.

Niki Gratrix So I think a really good thing to do would be, if you could, to actually share some of the basics of the four phases, especially as they relate to chronic fatigue and ME and those related illnesses, touching on all three of those dimensions that you mentioned there, the cultural, psychological, and physical.

Patricia Fennell Okay. And, Niki, if you hear me skip something, please feel free to interject and ask me specifically about it. But here goes.

So we have four specific phases. We have Crisis, Stabilization, Resolution, and Integration. So phase one, two, three, and four: Crisis, Stabilization, Resolution, and Integration. And, at each one of those phases, we look at three domains, three areas. We look at the physical. We look at the psychological/spiritual. And we look at the social/cultural. And we come at each phase from each one of those domains.

And when I say physical in this regard, one way to think about it is how do people physically move through the world? How do they organize their time? How do they manage their energy? How do they manage it in relationship to activities of daily living: work, play, health, development, self-care? How do they do it in relationship to all the tasks in their lives? So four phases, three domains in each phase, and we look at each one of those.

Now, mostly people come to clinicians like me or other people when they're in phase one or in phase two, when they're either in Crisis, and they're suffering tremendously, or they're in Stabilization. They've been trying the same things, the same interventions re-

peatedly. And things just aren't changing. Or they're not changing the way that they would hope them to or they would expect them to.

So we call that getting caught on a loop of phase one and phase two – they're in crisis, they stabilize sort of, and in an effort to capture their pre-crisis life, they get on this loop.

And they may gain enough ground, but the fatigue becomes too much. Among the other symptoms of CFS/ME (and this is with other complex illnesses, as well), they may have some cognitive impairments.

They have some neurological changes. They have trouble thinking. They have trouble having enough energy, depending on how severely they're affected on any given day, to do anything – to wash dishes or wash their hair, let alone go to work.

So we find that people in the Crisis phase can present from that perspective. Or they've gotten enough assessment and treatment from a few different places that they are now able to stabilize their life, but they're trying to go back to the life they had before. They're trying to be cured. And part of how I think about this is, I can't cure myself of lupus or MS or CFS or ME, any more than I can cure myself of my soft teeth.

The question is, how do I fix them and then manage them all the time? I don't want them to basically be a disease that's attached to a person, rather to be a person who also has maybe one, maybe two, maybe three complex illnesses, because it's frequently not one diagnosis per customer over a lifetime. We usually get a few of them. How do I manage those and still have a life?

So at that point, we have to introduce people to new rules, new attitudes, new interventions, so they can have their whole life and go forward and not try to constantly capture the pre-crisis life. The past is the past. How do we go forward?

And one other thought on this, we very specifically chose phases, not stages. Stages imply that you go through the stage like a developmental life stage. And you're done. And you don't go back. But phases are more fluid. They're more dynamic. And what we found is that when people get assistance and they navigate their way through the four phases, once they've learned to do that, now they have a cognitive map. Now, they have a way to think about what they're experiencing.

As life continues, if you have a chronic complex illness, if you have CFS, you're going to have blips. You could have a relapse. These things happen. So it becomes, "How do I work with that? How do I integrate that into my life?" Integration versus cure. "How do I manage that and have a full life without seeing a more difficult period as failure?" It's not failure. It's part of what comes with the territory.

Once we teach people how to do that, and once they navigate once successfully, it becomes a game changer. It doesn't make everything easy. But it really makes a difference in terms of how they manage going forward.

Niki Gratrix Fantastic. And very interesting. And I was just going to ask you about a few of the phases in a little bit more in depth. When I first read your work, what really struck me, was this aspect in phase one, and it also happens in phase two, as well, especially for chronic fatigue syndrome patients.

What happens is because it's a stigmatized illness and not understood, the patient's reaction to him or herself is self-shame, and then also the reactions of others, and you said that was traumatizing to the patient.

And now, within chronic fatigue, we now understand that emotional trauma, especially adverse childhood events is one of the risk factors for the onset in later life. And then they become ill. And then they have trauma. And I was like, this is compounding it. So I think this is an aspect that's totally not understood. And it was your model really picked that up.

Patricia Fennell Well, you raise a very important and interesting question, and one I get asked by clinicians that I'm working with, whether it's physicians or nurses or psychologists or social workers. Sometimes they have said to me over the years, "Isn't this CFS/ME all psychological?" No. Are there psychological aspects? Of course, there are. Are there adverse childhood events for all CFS patients? No. Are there for some of them? Sure.

And this is true for a lot of patients, whether they have CFS or not. But here's the interesting thing. If you have a poorly understood disease – and God knows this one is – the experience of the illness is traumatizing in and of itself. Now you may have some childhood adverse events, you may not — but the likelihood of you being further traumatized is high because illness is traumatizing in and of itself.

The experience of a CFS crash is brutal! It's so debilitating. People suffer in so many ways. I don't have to outline that here now. But it is brutal! If you then add to that, that people are then possibly further stigmatized by family or friends or the medical community or their work community, this adds to their burden tremendously. Tremendously.

Within the medical community, we might think of this as something that's called iatrogenic illness. This is what happened to me. I was a hospice worker, as I stated earlier. And my appendix burst, and I immediately had to go in for care. And while I was there, I contracted a secondary infection. So while they were caring for me, I contracted something secondarily.

Now, in the trauma world, it can be argued that while you're being treated for one thing, something else can happen as a result. So say the person is seeking help from a practitioner because of the symptoms they're having with CFS or ME or fibro, for example, and that practitioner doesn't understand, doesn't really appreciate the extent of what this person is experiencing, the person could potentially be traumatized further. So there are many examples.

One has to keep in mind with this is that the thing with chronic disease, the thing with the chronic complex illness, is that there are multiple opportunities to be traumatized because you have to keep interfacing with care providers. So this is something we work very actively with teaching clinicians, physicians.

Now, I think things have mightily improved than, say, 30 years ago, 20 years ago, even 10 years ago. And we also actively work with our patients and their families teaching them how to manage how other people, whether they're peer providers or friends or employers, might respond. Often people don't understand chronic experience, so that's a piece of what many patients experience.

But I want to stress, whether they've had a childhood experience or not (and they may very well have had, which can certainly be a contributing factor) the disease process in and of itself is traumatizing. And then how others respond can be, as well. So these are all aspects that we try to educate folks about, and really in terms of illness etiquette, teach them how to manage being at the family party or going to a new doctor's office.

Niki Gratrix This is so important what we're talking about here because this is where you mentioned about people cycling back between phase one and phase two. I saw that so clearly in my own clinical experience with patients. And it's tragic because so much of it is just to do with understanding how the phases work. So this is why I wanted to talk about it more.

And also, if somebody's not moving into phase three, there's this denial happening. And the really big thing that I got from your work is that in phase two that if somebody is effectively in denial about the illness, they're still trying to be the person they were. They're still trying to keep up with their schedule. We use the Enneagram type, the psychological typing system in the clinic. And it's a big theme on the summit. And we have the achiever type, the helper type, various *raison d'être* for the psyche, the reason the person's alive. And suddenly it's very difficult giving that up. Who they are? So they just go into denial and then keep going back into phase one.

Patricia Fennell Right.

Niki Gratrix So phase two, I just wanted you to expand on phase two because you're talking about effectively an ego death.

Patricia Fennell Right. You're raising a really good question. And there's a few points there. So here's the denial. Let me make it even a little bit more complex. Let's say the person is doing pretty well. They're starting to move towards, "You know what? I can't be who I used to be." Like the author said, "I can't go home again. I can't be my pre-crisis self. I can't undo the past."

But the people around them may be having a difficult time accepting that this, in fact, is chronic. And that is not a bad thing. We can have chronic conditions. We can have them. We can live with them. We can work them. We can still have a whole life—a whole life.

So frequently, we will see patients in our clinic, in our system where...And this speaks to the social-cultural aspect. I was working with this lovely family from a different part of the United States. And the young man, an engineer, CFS, early 20s, lovely young wife, couple of kids already. He was struggling with functioning at all. This was a few years back. And the level of understanding about CFS then was not as evolved as it is now, but even so.

Her parents, who had loved him initially, did something that people frankly normally do. And this speaks to the trauma aspect. This also speaks to the denial aspect. And it speaks to the phase aspect. They began to be suspicious, began to be concerned. Had their daughter chosen poorly? Had she somehow picked a faulty person?

They were having trouble managing their thinking about the reality of what was now part of their family system. And they didn't want it. And they wanted her to leave him,

which created trauma for her. She wasn't the person diagnosed with CFS. She was the most traumatized. So denial comes in different parts of the system.

Or, for example, you may be someone living in the United States. And you may be part of your particular space within the United States. Your healthcare system may be in whatever state it's in currently, so to speak. And your clinician may only have on average 9 to 12 minutes to spend with you. So that clinician is getting a lot of pressure for you not to be chronically ill, for you to be cured. But that's the definition of chronic. You don't cure it. In my framework, you integrate it.

So the denial aspect in phase two where people are being pressured to return to their pre-crisis self comes from lots of places. It doesn't necessarily have to come from the patient, the identified patient themselves. And when we assess folks, we do look at that whole, whole package. And we look at the culture and context within which they work: their religious orientation, their ethnic orientation. These are all aspects that weigh heavily on how this person's illness experience is going to be, frankly, allowed.

Niki Gratrix Yeah. This is so important. In Ken Wilber's model, this is the bottom-left quadrant. So it's this cultural aspect. And I have so many examples similar to yours. I had one patient, he was the CEO of a bank. He got chronic fatigue and basically became a Yoga freak and totally into this alternative life. Loved his new life, but his wife felt like she got a raw deal. She married a CEO of a bank. And now she had a Yoga freak. And she wanted to leave him. And she did.

And so what really strikes me in your model, as well, is in phase three, they've had enough. As if it wasn't enough in phase two, you would hope things started to plateau. But, no, this is where people actually will end up most likely to leave the person. So there's even more loss and grief, as well as going through an existential crisis.

Patricia Fennell Yeah. Right. Let's talk about that for one second. When I first was writing these phases actually back in...I think the first time I published them was when I think was, believe it or not, I think was 19—oh, my goodness—90. Anyway, I didn't want to say what year it is, but early.

I wanted to call phase three the existential crisis. And my editors at Wiley said, "Oh, don't do that. Please don't do that to us." But this is the deal. In phase one, in the Crisis phase, what we experience...I'm going to speak from the perspective of the patient for a second.

But we can all imagine each hat. If you're an MD, if you're a general practitioner listening to this, put on that hat, but also put on the hat of your child or friend or family member, because fatigue as an aspect, not just of CFS and ME, but of all chronic diseases, is a hallmark. And half, well over half the U.S. population in 1995 had at least one, if not two diagnoses that included fatigue. This is an awful lot of people. So whether you're listening with the hat of the patient or the parent or the spouse or the child or the clinician, this is going to affect all of lives. It's just a matter of time.

So in the Crisis phase, you're feeling, "Oh, my God! What's happened? I don't know what's different with me?" Nicole wakes up one morning. And this is one of the ways we talk about it in one of the books. And we say Nicole wakes up in the morning. And she hadn't been feeling so well. But she's got a couple of kids. Things are rocky in the marriage. She's starting to go through a divorce. She works...Okay, let's say she works for the bank.

And this goes on for a few months. And she's getting worse. And now, she's noticing that she's forgetting where she's putting stuff. She's getting confused. Well, typical CFS thing. But not just CFS, but other things, too. She is confusing her children's names. She can't remember them. And if she goes down the stairs twice, she's so tired, she doesn't want to go up a third time.

She goes to her clinician. The clinician's a nice woman. But she's got 9 to 12 minutes to spend with her. But she likes the physician's assistant, too. He's a real good guy. Anyway, maybe she's depressed. Maybe she needs to do additional things. She can't imagine how she's possibly going to do additional things.

But in the Crisis phase, she's scared. She doesn't know how to describe it. She doesn't have language for it. And in the Crisis phase for somebody with a chronic, poorly-understood illness, it can take up to three years to get diagnosed. That's a lot of time and ambiguity. It's a lot of time trying to figure out what the heck is going on? So people are scared.

Now, by the time they get through some of the Stabilization stuff, and we don't have a lot of time to go into that now, but if with assistance they are now starting to move past, trying to. They've gotten through the Crisis phase. They've stabilized a little bit. With our help, they're stabilizing differently. It's more of a genuine, "Now, I'm moving into integration. I'm not trying to capture my pre-crisis life."

Now, as I approach phase three, this is the time of actual real loss. You can't go home again. You can't be who you were before. And that is painful, sad. That is the dark night of the soul. And I would argue not for the time at the end of the tunnel, but for the time in the tunnel.

Part of what we teach, what we argue in phase three, in matching intervention to phase, that this is where spiritual traditions can come in...It can be a whole variety. It doesn't matter. But a whole variety of traditions here are helpful for people to develop meaning about their suffering. They have to develop meaning. They have to develop a narrative about why this has occurred. "Why me?"

But this larger spiritual work is the work of phase three. In order for that to be effective, they have to do the work of phase one or phase two, so lots of different interventions. We do our interventions phase by phase. We match intervention to phase.

So, for example, if somebody's in the Crisis phase, and they've been traumatized either advertently or inadvertently by a well-meaning medical professional, anything can happen. They've been given the wrong medication. They were not taken seriously. Any number of things could occur. A really good intervention in phase one could be for some trauma interventions from cognitive behavioral work. That might work really well for you. We do very specific interventions to stabilize them in phase two.

But phase three requires, I would argue, older, very frequently spiritual work, though it doesn't have to be. It doesn't have to be. We work with a lot of folks who are frankly atheistic. That's okay, too. But they have to develop a narrative meaning about their experience in order to have that full life. And that requires bringing in other kinds of traditions, if that makes sense.

Niki Gratrix Yes. Fascinating. And are there more examples you can give of matching treatment intervention to the phases?

Patricia Fennell Sure. So let's think of it this way. And in fairness to everybody, with 180 hours of curriculum, and we're training folks, and we do it actually one-on-one with the individual. But we also do it with the clinicians. And we develop cases for folks.

So we use instrumentation and interviews to figure out what phase someone's in. We also use it to figure out what phase the organizations and people are in around them. So what state is the family in? How are they going? What kind of healthcare do they actually have? What's their workplace like, if they're actually still able to work? For example, a lot of people can. A lot of people can't. It also depends what we're now going to do for them, based on whether they're in Crisis or Stabilization.

And then with that assessment piece, we look at domain by domain. We look at the physical. We look at the psychological, spiritual, where they're at. We look at the social. For example, let's say the person is in the Crisis phase. Okay. So they have been going along. And let's say their introduction to CFS...And there's been a lot of different ways that people come to it. But let's say they had been exposed to a very nasty flu. And they don't recover. And for whatever part of the world, whether they're in Australia or the United States or however they came to it, post Lyme, whatever it is, okay.

But they're having what would appear to be a real CFS manifestation. And they're getting a variety of different diagnoses. They've seen lots of different clinicians. Everybody has something different to say. Everything's conflicting. Maybe their boss believes them. Maybe their spouse believes them. Who knows?

So they are in personal hell. They are terrified. And they don't even have language to describe it to themselves. Let's remember, if we're talking now about a CFS/FM person, ME person, the likelihood of them having cognitive impairment, memory impairment, calculation impairment, a whole variety of things is pretty good. A lot of people do, all kinds of neurological impairments.

So we work to contain the crisis. We do a lot of traditional and our own trauma-containing interventions. It could be cognitive behavioral. It can be very physiological. We're trying to contain them so that they don't continue to add to their physical distress. Physically, we begin to modify some of their behaviors as much as we can, as much as they will allow, and the family and the situation will allow. And we work a lot with the level of fear and cognitive dissonance that they're experiencing. And one of the most difficult things for folks is the loss of control. We're working with that. And we're working with the amount of ambiguity. They are now swimming in a sea of ambiguity.

And it's terrifying. So we're containing the crisis. That is the clinical goal for phase one. In phase two, now we're beginning the hard work. Once we've got them more or less contained...By the way, we're also doing this with their medical professionals. So, for example, they may go in to a medical professional, who says, "Okay, I want to change your diet. We have to change your diet. I want you to take these different medications. I want you to do all these different things."

And part of, for example, on the social/cultural perspective, we have to say to the people who are intervening on, say, the physical/medical perspective, "Wait! Wait! Wait! All

these things can't be done at once." Even if everybody agrees these are the best choices, no one can complete it all. They have less energy. They have more disruption.

We can't ask them to do all these things upfront. They won't be able to do it. And we're setting them up for failure. And we're setting them up for the non-compliant patient. And you don't want to do that. So that's just the tip of the iceberg on some of the things that we could do for someone in Crisis.

We do a whole series of different things as they begin to stabilize with all the different disciplines they're working with. So we're going to do different things with people on the physical domain. We're going to do different things, say with physical rehab, PT or OT, occupational therapy. So those are some of the medical professionals that use our books as textbooks. And we train and teach, etcetera. And how do you then intervene at that phase differently?

Niki Gratrix Yeah. Actually, it's fascinating because I would just say this is a note for the audience who are functional medicine practitioners and they're nutrition practitioners, they really need to be aware about the phases. Because as just as an example, when somebody is in the trauma stage, it's being in the fight/flight response. So you're not in the healing phase. So anything you're doing on the biochemical level, that's not a time to try and start detoxing somebody or doing big interventions.

Patricia Fennell I absolutely agree. I absolutely agree. You have to contain the crisis before you hit them with anything else. You'll just knock them off their pins. You will absolutely knock them off their pins. And that also assumes that everybody around them is available to pick up the slack. Who's going to drive this person?

And we treat people from all over the world that sometimes come to see us, however we do it. But depending on where they live and the traditions in which they live, how is this person going to be driven? Where are they working? You have to be able to accommodate, in some way, shape, or form how their life has been disrupted by what has occurred.

Niki Gratrix Yeah. Absolutely. And also another really interesting thing, even in phase two, one of the key things that Dr. Leonard Jason pointed out, and that's been on the summit a lot, is that for people—chronic fatigue patients—a prerequisite to getting better is pacing. And now that's not curative. But the pacing aspect is so important if anything else is going to work.

So even if a physical intervention's going to work, which another big theme on this summit is this whole area of mitochondrial function, that if somebody's in denial in phase two, trying to be their old self, not pacing, still trying to do all their scheduled work, there's no way that you can heal mitochondrial function if somebody is constantly pushing past their boundaries in boom and bust. You might as well forget it. So it really hit me so hard that this is how important your work is.

Patricia Fennell Yeah. Right. And I would say we started writing about this back in the 80s. We didn't use that particular term. But we talk about how do we modify our activities. And, for example, in our Workbook, we have a series of exercises that we work with. Physicians use the Workbook with their patients. Some people do it. We do it with people where we help them identify the specific activity areas of their life. We take those

apart into what we call “the four activity food groups,” just being cute, I guess. And we help them understand what has to be modified.

So, for example, it can be argued that we all have what I’m calling these activity groups. These activity groups include work, play, self-care, and community. And that includes family etcetera, etcetera. When people begin to get ill...This is very consistent, okay, certainly, here in the U.S. And this is cross-cultural.

When people begin to get ill, the first thing that goes for women—and there’s also gender issues here, okay—women they will let go off their self-care first. It’s gone! Well, they don’t have the...first they frame it as the time. But the truth is it’s the energy. They don’t have the energy to continue to apply makeup or just care for their bodies the way that they used to or exercise. So that’s why, for example, when they go to their clinician and their clinician says in the 9 to 12 minutes, “You need to go exercise.” And they’re like, “What?! How do I begin to integrate that?” Okay.

They’re struggling to now keep up with however their families are trying to “play,” which, by the way, helping with family play for a woman is work for her, usually. Just want to point that out, because if the family is taking all the kids to a hockey game, then she’s taking the kids usually. There’s a lot of work for the woman in that. Plus, she usually has a job of some sort. She has to bring an income. So her self-care begins to erode.

And then what she has to let go of is usually the family pieces, the community pieces, her friends. And then the last to go is work. The last go is that particular piece. So this is just one example. Again, it can be, it’s ethnically driven. It’s gender driven. It’s culturally driven. But we look at those aspects of their lives. And so we are restructuring them...I actually joke with people and I’ve always said, “There are only so many BTUs, British thermal units. There are only so many units of energy that you have in a day. Anybody does. Some people have 1,000. You have 200.”

Or we also put monitors on some people. Some people have 10,000 steps in them a day. CFS patients often have 2,000 tops. So it’s how many steps do you have? How much energy do you have? But then we have to really go dole it out and look at how it’s used and how we can reshuffle that deck to help them move from Crisis into Stabilization. I have to reduce that symptom load in order to be able to then add anything else like a cleanse. Or I’m going to fry them.

Niki GratrixYep. It’s fascinating and just one small comment from me, as well, here. The phase where someone is in trauma or they’re not coming to terms with the limits on their energy, that would cause an inflammatory expression. So the behavior translates into the inflammatory expression.

So the researchers who are only looking at the biochemical paradigm will see these phases. But if they don’t understand what the patient’s going through and why their behavior’s the way it is because they’re in phase two, they’re going to try and look for a biochemical-only reason for this chronicity. And I’m just raising that because this is so important when they’ve just done a study this year.

Patricia Fennell Right. Absolutely. And one of the things I like to say, and I say this often, is 500 or 600 years ago, Descartes made this deal with the church. And the church got from the neck up and science got from neck down. And that’s been useful for lots of rea-

sons like developing science, etcetera. But it's created this false dichotomy between head, heart, and body. And so this is part of what we're struggling with now. Psyche and soma is one in the same.

So when I'm training clinicians and I'm saying, "If you are a psych clinician, you have to begin to think about thyroid. I know you weren't trained for it. But we have to begin to think about that and how do we put that into our curriculums." We're helping nurses now develop curriculum for a whole variety of things, and physicians. We have to work concurrently. Whether we were initially trained on the psych end or we were initially trained on the medical end, the physical end, you have to now concurrently look at both.

You can no longer talk about depression as a psychological-only phenomena. You have to consider reactive depression. You have to consider organic depression. You have to consider depression that's part of disease process in someone's literal brain while you concurrently think of depression as being reactive to the fact that their brain hurts. And they can't do what they used to do. These things are not mutually exclusive.

So when we're talking about somebody having profound fatigue and cognitive impairment and any number of other symptoms that are really torturing them, tormenting them—movement disorder is also part of the phenomena—whatever they're experiencing, they may have psychological components that are part of the actual physical expression information.

There was a very interesting study recently. And I will unfortunately not be able to quote you from where. But it made it into the popular press, I think. And it was talking about the relationship between major depression, allergy, and inflammation and the researchers were saying that part of what people may be experiencing in depression is inflammation. And, in fact, when they are having a flare of their allergies, they may also be experiencing a flare of their depression because the brain swells, so to speak, colloquially. These things are no longer separate.

If I'm teaching people who've been initially trained, we all have now the responsibility to think on both sides of the court. We have to bring that split seriously back together. And that then has to be encased in the context of the illness experience. Where do they live? What's their gender? What's their religious orientation? What are their expectation of family and community and workplace? You cannot separate these things out.

Niki Gratrix I couldn't agree more. And just coming to the final couple of questions here, or comments, the person in phase four, we haven't talked too much about that. But would you just expand a little bit? What does the person look like, feel like, what's going on in their world in phase four?

Patricia Fennell Well, this is really interesting. And one of our instruments, we were measuring again where patients are in the phases. And this is some time ago. I forget which studies these were. But these were a couple of studies we were doing with one of my instruments. And patients that make their way into three and four, they may or may not be physically better.

But what has changed is they have come to understand that relapse, remission is a part of not only the CFS/ME process, but it's part of life. We will relapse and remit. We suffer. We learn. We integrate. We do not capture that pre-crisis—the most recent crisis—be-

cause I like to think of it as the crisis du jour of life. How do we integrate it and go forward?

So that person in phase three and phase four, that person is in increasingly, if they started a different narrative, a different story in the existential crisis of phase three, when they had to ask the big questions, “Why me?” Why God? Why suffer like this? Why continue? And I choose to. I’m making meaning for my life. I am developing a different way of going forward. I have a new set of skills. I have a new understanding. It’s not going to be easy. But I choose life. I choose life.”

When I then go into the Integration phase, I am then in a space of, “Well!” And here’s the thing. We don’t stay in any of these phases. That’s the point of chronicity. That’s the point of phase. We move back and forth. If you can be in a fairly...

And I use myself as an example. I think I’ve been doing pretty well in phase three. A dear friend of mine—oldest, dearest friend—passed away a few weeks ago. And have I been in a tiny crisis phase? Yes. Is it full-blown? No! Why? I know how the phases move back and forth. I know the skillsets of what I need to apply.

So if I’m in the Crisis phase, I know how to restabilize myself. I’m going to integrate this into the meaning. Why did this happen? Who was this person in my life? How do I take it going forward? How do I use it? I’m using it right now. Move into a place of integration. And I will visit it. But I will move back and forth. And that’s okay. That’s not failure. That’s chronic. That’s the point. That’s life.

Niki Gratrix So there’s two things that are really interesting about that. What you just said. One is the thing I noticed with many patients. When they do have a relapse, we spend a huge amount of time detraumatizing a relapse. So even if a relapse happens, we don’t even call it that. We don’t like the word. We just call it a blip.

And the interesting thing is when someone, exactly as you’ve just said, that they approach it with a phase four approach of, “This is okay. I just know I’m going to be a bit more limited for this next week or so.” At the beginning, many patients will respond with a massive crisis to their relapse, and actually will make it much worse.

This is also a stress-induced illness. So that’s the tragedy of going between phase one and two again. Well, simply because people just didn’t understand they can be calm and realize as you say they can be in an accepting mode during a relapse, they are actually also increasing chances of cure longer term too. But not that it’s a given.

Patricia Fennell It’s a fine line. You have to concurrently be able to say to people, “Here is the deal.” And I was doing a phone consult with someone. And she is taking care of her elderly spouse and her mom, who’s over 100. She’s been a CFS patient. She has a few other diagnoses. But she’s been a cancer patient. But it’s the CFS that she has to worry about managing.

So when we were talking earlier, it’s this line. I said, “So how are you doing?” She said, “I’m concerned. But I’m managing. I’m watching the different symptoms and I’m making sure that I’m resting more. I’m only talking a certain amount.” So it’s this line between we want people to, on the one hand not ultimately be terrified that they’re going to take

the big crash again. Though it's understandable they'd be afraid. You have to allow that fear, while they're using what they've learned through the phases to manage it.

Niki Gratrix Exactly.

Patricia Fennell You have to acknowledge the fear. But then also say, "Okay, but we're managing. We're managing going forward." Both things are true.

Niki Gratrix The one last thing I want to say. It's amazing how this process that you've described, the phases that people go through in spiritual traditions, people will voluntarily go through an ego death...This is a forced thing on a CFS patient. And they've not asked for it. But in the spiritual traditions, you are actually voluntarily going through these processes as part of the ego death.

And just not everybody knows about the spiritual traditions. But this is in some ways how I most relate to my patients because people often say to me, "Haven't you had chronic fatigue or a related illness?" And I would say, "No, I have a deep amount of spiritual and consciousness work that I've done." And that is not easy work either. So it's always amazing to me. It's another thing I just picked up from your work, as well, where you really did bring in the spiritual aspect.

Patricia Fennell We've written about it a lot. And then when I did my first book in the first edition of it, and it came out of part of my own experience, it was a very severe crash. And I love this expression. And I won't tell you who we've tried to attribute it to. But it's from a lot of different places. And it's, "My barn having burned to the ground, I can now see the moon."

So within the spiritual tradition, people are shedding all of what came. And now, we're looking at who am I now through this suffering? What has come out? Part of what is difficult I think for the people that we're working with that they often didn't choose this path. It was imposed. This is the imposed path.

Part of the expression I use for people in Stabilization phase is it's about chuck wood carries water, old Buddhist. Fall down 7 times, get up 8. This is part of the discipline of the monastic experience. And part of how I see faith, too, especially if people are heavily afflicted is you're being forced into the monastic experience, where you're being forced into a discipline that you wouldn't have chosen. But it has chosen you. So that's certainly part of how we think about it.

Niki Gratrix Lovely. So fantastic. Patricia, it's such important work. It's phenomenal work that you're doing and quite rare, I would think. And it's so important. So I'm so glad that you were able to share your time with us today.

Where can people find out more about your work? Including, is there a questionnaire available where people can find out where they're at? Or do they need to go to a professional for that?

Patricia Fennell Well, we come at it with a few different ways. If they go to our website, which is AlbanyHealthManagement.com, it's all spelled out there. I'm sorry it's one of the longest URL addresses in the world, but nonetheless, AlbanyHealthManagement.com. They'll see a lot of information about the phases and the different things we do and how

we consult with patients and their families, consult with clients, and how we train and work with all manner of professionals, professionals, and organizations, etcetera. We have books. We have materials.

And as far as the specific questionnaire about what phase they're in, that's something we like to do with people. We'd rather get them reading a little bit first. And so we can help them use that information in a way that's going to benefit them the most.

Niki Gratrix Lovely. So thanks again, Patricia. It was fantastic! Very informative. And I thoroughly enjoyed the conversation. And I think our audience would have hopefully greatly benefitted from it, as well. So thank you very much!