

Grief and Chronic Illness With David Kessler

Host: Rebecca Gillett, MS OTR/L Guest Expert: Courtney Wells, PhD, MSW, MPH, LGSW

Grief is most commonly associated with death, but anyone who has experienced loss as a result of chronic illness knows the pain of grief all too well. People with arthritis may grieve the loss of physical abilities they once took for granted, the loss of their way of life or the loss of the plans and dreams they had for their future. Grief is an emotional minefield that can be tricky to navigate and often devastating.

Few people have a better understanding of grief than David Kessler, not only from his personal experiences but also from his professional life. An internationally recognized expert in grief and grieving, Kessler shares his knowledge, experience and advice in this episode of the Live Yes! With Arthritis Podcast.

Kessler co-authored two books — including On Grief and Grieving and Life Lessons — with Elisabeth Kübler-Ross, best known for helping to define the "stages of grief." His new book, Finding Meaning: The Sixth Stage of Grief, is the sixth he has authored on death and grief. Kessler, who has experienced significant tragedy in his own life, including the death of his son, has spent his career counseling people and teaching health care providers, first responders and many others about trauma, end of life and grief. He gives talks and workshops on these topics and he founded the website grief.com, which provides a wealth of resources for people who are dealing with grief as well as for professionals.

Guest cohost Courtney Kellerman Wells, PhD, MSW, MPH, LGSW, is assistant professor and field coordinator at the University of Wisconsin – River Falls, specializing in the psychosocial aspects of chronic illness and disability, social work in healthcare, adolescent development and qualitative research. Having grown up with juvenile arthritis, she has personal experience with mental health challenges and is now a researcher who focuses on mental health during times



of transition. She is also an Arthritis Foundation volunteer, advocate and a true Champion of Yes!

Additional Resources

Grief.com

Finding Meaning: The Sixth Stage of Grief

Make Mental Health a Priority (podcast)

Arthritis and Grief



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PODCAST OPEN:

You're listening to the Live Yes! With Arthritis podcast, created by the Arthritis Foundation to help people with arthritis — and the people who love them — live their best lives. If you're dealing with chronic pain, this podcast is for you. You may have arthritis, but it doesn't have you. Here, learn how you can take control. Our host is Rebecca Gillett, an arthritis patient and occupational therapist, who is joined by others to help you live your Yes.

MUSIC BRIDGE

Rebecca Gillett:

Thanks for joining us on this episode of the Live Yes! With Arthritis Podcast. When you are first diagnosed with arthritis or some form of chronic illness, it can bring on so many emotions. It's a roller coaster ride as you continue on your journey with your diagnosis, whether it's rheumatoid arthritis, osteoarthritis, lupus or gout, or maybe it's even your child with juvenile arthritis. There's an overwhelming number of obstacles that can arise and so much to learn about your condition or your family member's condition.

Grief is something that's usually associated with death and loss. But people with chronic conditions know grief all too well, whether you're recently diagnosed or a veteran of arthritis like me, due to our loss in identity, a loss in the roles that we play within our families, our workplace or our community.

There can be a profound sense of loss for what we thought we could do, who we thought we could be, what we thought our future would look like. We may have to give up a hobby or an activity that brought us joy. Today I'm really glad to have this discussion about grief when you live with a chronic condition. It's something we don't often talk about. So today let's talk about it.

I'm so glad to have with me a special guest host, Courtney Wells. She's a returning podcast co-host with me. Welcome back.

Courtney Wells: Thanks for having me.

Rebecca:



Courtney is assistant professor and field coordinator at the University of Wisconsin. She specializes in the psychosocial aspects of chronic illness and disability, social work and health care, adolescent development and qualitative research. As a social worker who grew up with juvenile arthritis, she has personal experience with mental health challenges and is now a researcher who focuses on mental health during times of transition.

She's also an amazing Arthritis Foundation volunteer and advocate and a true Champion of Yes. So, I'm so happy to have you on Courtney. And am so excited to introduce our guest speaker.

David Kessler is the world's foremost expert on grief and loss. His experience with thousands of people on the edge of life and death has taught him the secrets to living a happy and fulfilled life even after life's tragedies. He's the author of six books, including the latest bestselling book, *Finding Meaning: The Sixth Stage of Grief*. He co-authored two books with Elisabeth Kubler-Ross, including *On Grief and Grieving*, that updated her five stages for grief.

His first book, The Needs of the Dying, received praise from St. Mother Teresa. David's personal experience as a child witnessing a mass shooting while his mother was dying in a hospital helped him begin his journey. For most of his life, David has taught physicians, nurses, counselors, police and first responders about the end of life, trauma and grief.

Despite his vast knowledge on grief, his life was turned upside down by the sudden death of his 21-year-old son. It inspired him to write his latest book, *Finding Meaning*. He is the founder of grief.com, which has over 5 million visits yearly from 167 countries. David, thank you so much for taking the time to join us.

David Kessler:

I'm so thrilled to be here with you and Courtney and everyone listening.

Rebecca:

One of the things that I've always talked about as a patient with arthritis, and even more importantly as an occupational therapist and a health care provider to others, is that people don't often think about when somebody has a chronic illness, how it truly penetrates their life and changes their whole path.

I've always thought about it as going through grief, and not just at the initial time of diagnosis, but every time I've had something else come up. This is why I wanna have this



conversation to highlight, you know, the emotional aspects that can be involved with having a new diagnosis or a diagnosis you've had for a long time. Maybe define what grief is first.

David:

Grief is change, and more specifically, it is a change we did not want. It's a change we didn't want. So, certainly when we think about so much of what folks deal with on this podcast, it's a change you didn't want. That's a pretty good definition for what most people deal with.

I always wanna preface some of the disclaimers about the stages, and we'll talk about why they don't have to be your model for grief. I just want people to know that. Elisabeth Kubler-Ross, in her book, *On Death and Dying*, in 1969 described five stages and a lot more. She talked about many other stages, and she talked about them as observations. And it's a little like she observed that the sun rose in the east and sets in the west. People, unfortunately, took it to mean: The sun rises at 6:05 a.m. for everyone every moment, and there's no change in that.

Rebecca: Right.

David:

The reality is the media wanted to grab something easy. So, of all her stages, they grabbed five and said, here's the five. I always felt bad for her 'cause so much of her work got reduced to those five stages. The stages, we adapted them together, I adapted them with her, for grief from dying, in our book, *On Grief and Grieving*.

Literally on page one, we say: They're not linear. You have many rounds with them. There's no one right model. In fact, we don't even know that there's a model for grief. And there's no right way to do grief. In fact, there's no wrong way to do grief. And grief is many more things than death.

People would come and sit down with her and say, "Elisabeth, I have this patient, this client..." and give us 20 minutes of background. And then at the end they would say, "OK, Elisabeth, now that you know their story, what stage are they in?" And Elisabeth would go, "Forget the stages. Just meet them where they are."

These stages we're talking about are: Denial, which is the "I can't believe this is happening. I can't believe this is happening to me." Anger: "I'm furious that this is



happening." Bargaining: It's two sides. Sometimes it's for the future. "Oh, if I do this, maybe this won't be," or "This happened because I did this," and it takes the form of guilt: "If only I hadn't done that." And then depression. But really, it's sadness. And then there's acceptance. And I think one of the myths about acceptance is that we think there's one big acceptance. Oh my gosh, we have a million, millions of little acceptances we have to deal with.

So, those are her initial five stages. And they're not in any order, you can do rounds with them. And you know, if you're like, "I don't like that model," no problem, it's completely fine. Do grief your way. It's the only way you can do it. The stages give them a little scaffolding to realize, "Oh yes, there's some things that help me make sense of this."

Courtney:

I find a lot, with the people that I'm working with, that they are being diagnosed as having depression. And maybe at times there's truth to that, but also that they are grieving and that isn't necessarily being recognized in that process. So, I'm curious about your thoughts on that.

David:

We all live in a quick-fix society, we so want to just fix things. I think if there's anything I say a lot that surprises people is, I go, "Well, I would expect you to be sad." Or "Given what you just told me, I would expect you to be depressed." Or "Of course you're crying all the time. I'm crying just hearing about this." I think we don't know how to normalize depression and sadness either.

Rebecca:

Yeah. We held a webinar last night for people who are recently diagnosed and had an immediate comment when we were done from someone who said, "Thank you for this blessed event. This is the first day that I felt hopeful and didn't end my day in tears thinking that my future was over."

David: Right.

Rebecca: You need some hope, right? Something to hold onto.

David: Correct.



Rebecca:

Just like you're saying: The stages were not meant to be linear. No one's experience is ever the same. We all don't fit in a perfect box.

David:

Right. In grief, we're taught by our family, by our society, by our religion, by our culture. Some people are taught: "Be strong, don't have feelings." Others are taught: "Be ladylike, don't be angry." Others are taught, you know: "Be productive, get over it. Don't whine in it. Don't wallow about it." All those things. And I think each of us has to go eventually, "All right, I'm dealing with some grief here. How, as an adult, not the way I was taught, how do I want to approach grief? How do I wanna do grief for me in my situation?"

Courtney:

I find often that the clients I work with, they are struggling because of the interactions that they're having with the people around them and their response to their grief. And how they don't know how to respond in a caring way, in a helpful way, to that grief. And then they get stuck in their process because of that interaction and that cycle that continues that. So, I would also love to hear your tips and ideas about how people can respond in a way when somebody is grieving that really is helpful.

David:

Yeah, it is really challenging. Our friends and family are trying to figure out what to say. Don't begin a sentence with 'at least.' "At least you know now, at least you could..." You know? Because it minimizes what we're going through, and we have a society now that wants to bright-side you. In other words, get you to look on the bright side. I can call that toxic positivity sometime.

I find when I don't know is not a good time to give advice. "Is that what you did when you got arthritis?" "Oh, well, I don't have arthritis." "Oh yeah. You know, I think I'm going to talk to some of the folks who are dealing with it because they really have the experience." I mean, there's gentle ways.

The other thing sometimes is, I'll say, you can actually say, "Ouch." 'Cause the moment you say ouch to someone, the person evaluates what they said, you know? "Ouch." Why? Well, oh my gosh, what did I do, you know? "That just wasn't that helpful, telling me to be happy I'm still alive or I could have cancer. I mean, I don't know that that's really helpful."



I think one of the challenges for people is: When you're in pain, emotional pain, physical pain, it's a hard time to teach the people around you. "I gotta deal with this on the inside and be the teacher?" And I tell people, you have permission to not teach for a while. Just ignore what they're saying. They don't know.

Rebecca:

I think you just captured that so perfectly, it's exhausting. It's exhausting especially for somebody who's new to a diagnosis. They're still trying to figure it all out and educate themselves, and to have to educate the people around you, it's almost like you want them to take the initiative to educate themselves, right?

David:

But the problem is: We live in a grief illiterate world.

Rebecca: This is true.

David:

We have to remember when we're going through it: No one gets up in the morning and combs their hair and puts their clothes on and goes, "I'm gonna be mean to someone dealing with something traumatic today." They love you and they're trying to be helpful, and they don't have the right words and they don't know how to do it. And if you can see the love underneath, that's helpful. And ignore the words sometimes. (laughs)

Rebecca: Just walk away.

David: Easier said than done.

PROMO:

An arthritis diagnosis can be overwhelming — learning about your disease, getting started on new medications and making lifestyle changes. But there are plenty of steps you can take to manage arthritis, regain control and get back to doing things you love. Get tips at <u>https://www.arthritis.org/newly-diagnosed</u>.

Rebecca:



Courtney, you've said this before in past episodes, that you do have to go through it and label some of these feelings that you're having to get yourself in a position to be able to reach some sort of acceptance for what you're struggling to accept.

Courtney:

Yeah, and for me it's taken my entire adult life so far. So at least 20 years of being in therapy, being a social worker, having this education and also doing the work myself. I have all these resources at my fingertips, and it has been so hard to label that and to even recognize that it is grief. I've never had a therapist use the word grief with me. That was something that came on my own.

David:

And aren't you grieving the life you had before the diagnosis and the life you may have before the most recent change?

Rebecca:

Absolutely. I've had 16 surgeries, and every single time I've had a doctor say, "Well, this looks like, you know, this problem, and the only way to fix it is this surgery." I go through all of that grief. I'm angry again that I have to deal with this chronic illness. I'm angry again that there goes my entire summer, and I don't get to enjoy it with my family.

And then I have to get to the point, well, maybe the reason this happened was to slow me down, and I needed a break. But every single time something has come up, whether it was a surgery or a new health issue to address, I have to give myself that time. I finally realized, like, I'm really grieving the life that I thought I was gonna have.

David: Right. So true.

Courtney:

Yeah, and I've come to think of it as I'm building up my grief muscles, that over time, like you said, it doesn't go away. Every time I go through this process, I get a little bit stronger, and it gets a little bit easier, and I know what's coming, and I know it will end. As I get older, that process becomes easier to walk through.

David:

I think that's an important point: that everyone does have to become their own grief expert. In the beginning of the pandemic, I was out walking the middle of the street with a friend. And a young woman comes running up to me crying and says, "I'm one



of your neighbors, we've met once before, and my wedding's just been canceled." And she burst into tears.

She goes, "We're gonna have to postpone it for three months now, there's not another date." And I talked to her about this is grief, and we chatted about it. After she walked away and thanked me, my friend said to me, "Oh my gosh, I can't believe she was going on and on about postponing a wedding that's going to be happening, You've had a child die; that's real grief. Hers is not real grief." And I said to my friend, "You misunderstand how grief works. You think there's a grief pie, and the one grief... there's a winner of the worst grief. And that person gets all the grief and there's a limited amount of grief."

And I said, "No, no, no. There's enough grief, unfortunately, in the world for all our losses." And you know, people always ask me: Which is the worst grief, is it this one? Is it that one? Is it all this? And I will say: The worst grief is always yours. Grief is in our heart; comparison is in our mind. To heal the grief we're dealing with, we have to go into our heart and feel it and not look at whose is worse. And who's got this and what happened to them? All those things are so important to get.

Rebecca:

I want you to repeat what you just said. Grief is in our heart and comparison...

David:

Comparison is in our mind. And you don't have a broken mind, you have a broken heart.

Rebecca: And grief is change.

David: And grief is change.

Rebecca:

That's pretty powerful. Don't devalue your personal experience. You have pain, period. No matter what's causing it, whether it's physical, emotional or whatever. You have pain.

David:



When we talk about meaning as the sixth stage that I've added, you know, how do we get to meaning? And the only way to get to meaning is about excavating that emotional pain. You know, we all would like a shortcut for pain. I would love a shortcut for emotional pain, but the reality is: There isn't one.

Buffaloes, when they sense a storm coming, they run into the storm, thereby minimizing the discomfort, how long they're in the discomfort. Humans, on the other hand, deny the grief, push it behind us. Don't acknowledge it and sort of live maybe not only with a chronic illness, but live with unattended grief, three feet behind us, that we're not dealing with.

And it's really important. And I think when I add this layer of meaning, people will go, "Well, wait a minute. There's no meaning in a chronic illness. There's no meaning in arthritis." I'll go, "Exactly. Meaning is not in the diagnosis. Meaning is what we do after." And it really has to make us think about what's healing. You know, so many people think healing means you're forgetting. Or healing means a cure, or healing means you're over it. To me, healing — the emotional healing we have to go through — is that the event, the circumstances, the situation, the diagnosis eventually no longer controls us emotionally.

Rebecca:

Yeah. And from your book, I wanna read an excerpt that I highlighted. The chapter is "The First Step in Finding Meaning." And the first paragraph: "The first step in finding meaning is the fifth stage of grief: acceptance. We don't like loss. We will never be OK with it, but we must accept it, even in its brutality, and in time acknowledge the reality of it." There are aspects of it that we may never accept, right?

David: Right.

Rebecca:

But we still can find some meaning in some of it.

David:

Right. And you know, to find the compassion and grace. I'm a grief expert. It didn't make my grief any easier. And I can actually remember my older son was diagnosed with a heart condition, and he was at UCLA here in Los Angeles. And I was saying to the social worker, you know, I forget exactly what I was saying, but she said to me: "It seems strange for me to tell you this, given who you are."



She said, "You are grieving who your son was, and you are not seeing who he is and the situation now. And I get you wanna advocate for him, but in order to do it and be effective, you are going to have to fully grieve the world that you were in with him and you wanted, and he was a football player and all that. And you are gonna have to fully grieve that, so you can come into this moment to advocate for him and be present for him."

And It's just as true about ourselves. We have to grieve the diagnosis and grieve the latest change or whatever we've dealt with. Or surgery, or treatment, or treatment failure, or whatever it may be. And come into this moment to find our emotional healing and advocate for ourselves, even if it's with our own family, that this is hard and you're never gonna get it. And by the way, I'm really glad you're not getting it.

You know, the thing is I have to remember sometimes when someone comes up to me and says something that is just crazy about even, you know, my own younger son dying, I'll go, "I understand that you don't understand. And in fact, I'm actually glad for you that you don't understand, and that you have the luxury of saying, "Why don't I just get over it? And it's really different once you're in my shoes and I hope you're never in my shoes."

Rebecca:

I think that's a great way to respond to people. When I talk about grief and chronic pain with other professionals, what I talk about is that it took me a lot to get through it, to be able to say, "This is my meaning, this is why I host this podcast. Why I volunteered for the Foundation for a long time and now lucky to be on staff because I'm helping other people in my own little way." I see it as a blessing, you know?

David:

You can read any of my books and substitute divorce for death or chronic illness diagnosis for death. I mean, it really is the same theories.

Rebecca: 100%, yep.

Courtney:

And I really like your point, Rebecca, about the blessing side of things. Ultimately, that's what helped me with my grief.



David:

And what I say to people is: Do you wanna find meaning? Do you wanna find healing? Do you wanna find life after this? You know, you're underwater right now and you're hitting bottom. And at some point you're gonna have this decision in the middle of the night in your quiet: Do you stay at the bottom or do you push off and swim again? And it's going to take time.

I also tell people, you know, meaning is really actually in small moments. Someone's going to hear this and it may lighten their burden just a little bit. "Oh my gosh, that's so meaningful." That's meaning, just this moment we're having it, if we can label these moments. Don't underestimate the bowl of cereal that you're having with your child.

Courtney:

I can share one of those moments for me that really did ultimately end up changing my life. But in the moment, it was a very small thing. I was in college, and my arthritis was out of control, and I was struggling with that and my mental health. And I started volunteering for the Arthritis Foundation. And I went to a support group for parents whose kids were newly diagnosed with arthritis. And I was sitting there next to my own pediatric rheumatologist, and the parents had so many questions.

But ultimately the parents wanted to talk to me. They were more interested in talking to me than they were in talking to my doctor. And that shifted my entire life because I realized, and I don't necessarily like the word gift, that this was a gift for me because I don't know that I believe that fully...

David:

Yeah. Because a gift you can return.

Courtney:

Right, exactly. (laughs) That day, I dropped all of my classes. I registered for organic chemistry and calculus and totally changed the course of my life. And it was that small moment when I saw these parents look at me as an expert, as a 20-year-old expert because of my illness, that was a shift, a major shift.

David:

Wow. That's wonderful. But I also wanna caution anyone listening: It can sound like it's happening because of what we do. And the truth is it's really happening because of who we are. And it's really about: Who can we be? We all have limitations. Who can we be within them and how do we hold them?



Rebecca:

I love that. There are a lot of people I know listening who are struggling to reach acceptance and searching for meaning in their experience with all of the change they're dealing with in their life. What advice do you have for them as they try to come out of it?

David:

I would say you may not come out of it. You may have to learn to live with it. I would also say, you know, it's not this gigantic acceptance that you have to accept. Can you just accept today? Can you just accept: This is what you're dealing with today, and let that be enough of a challenge? Meaning will come in its own time, in its own pain, in its own way. If you just work on the pain and releasing the pain and allowing it. And the last thing I would leave you with is that: What we run from pursues us and what we face transforms us.

Rebecca:

That's really good.

PROMO:

All over the country, we have support groups to help you manage your arthritis. Groups may meet virtually or face to face, depending on your location and the pandemic. Connect with others who care at <u>https://connectgroups.arthritis.org</u>.

Rebecca:

One of the segments we have in the podcast is: We put questions out there on social media and ask people what their experiences are. So, we asked: Have you experienced grief with your arthritis diagnosis? A lot of activity on Instagram and Facebook and people responding to that. And what types of things have you had to give up because of your arthritis?

This person said, "I've not thought about it as grief, but I guess I do mourn the freedom of complete movement I once had. I like to go, go, go, and that's not been the case these last five years with osteoarthritis."

David:

I hear the huge change they've had in their life. I hear how they miss the ability to go, go, go. This isn't really about self-help. This is about self-acceptance. And I accept them exactly where they are in that struggle.



Rebecca:

Yeah. A couple other comments: "I have grief for my 10-year-old daughter with arthritis. I worry about her future and grieve for her, knowing her life will be different because of her diagnosis."

David:

So, here's the challenge with that: Whatever her daughter goes through, as a parent, it is heartbreaking. Take that grief somewhere else, not to your daughter; take that grief somewhere else to deal with it. So that, in that moment when your daughter is excited about this, she doesn't look at your face and going, "You're looking like, oh, if only you could do that."

In her world, it is what it is. And we don't want our children to see this face of the grieving parent for their whole life, grieving what they can't do. They're gonna have enough of that on their own. We need to let them discover those moments because the moments we're grieving for them may not even be what their grief is about. We have to make sure, as adults, we handle our grief other places, 'cause it's very valid, and it's very painful to watch.

Courtney:

I've heard a number of adolescents say that they feel it is their job to protect their parents from this difficult process. And that is on top of them living with the illness.

David:

Right, of course. I can't tell you how many parents I have that are like: Help me fix them. I mean, they don't say it that way, but it's like, help me fix them emotionally. And I'll go, "You handle yourself emotionally, that's the biggest gift you can give them."

Rebecca:

We often hear people say that it affects their marriage. One comment was most definitely he experienced grief with his diagnosis. "It ended my marriage."

David:

Judgment about grief causes divorce. Arthritis and illness inherently doesn't cause divorce. All the emotional baggage, that's either there before and comes up with it, for both parties, is ultimately what can be the challenge.



We all have to, in some ways, give up what we thought should be for what is and make the most of what is. And part of what I try to do in my work is: So many of us have the belief, if my child died, my life would be over. If I got arthritis, my life would be over. And you know, I think we all try to sit here as an example of when the worst things happen, life can still be worth living and happiness is still possible, and joy is still possible.

Courtney:

We often share examples of people struggling and maybe how they've learned to live with arthritis, but we rarely go to this other place of how they have learned to make meaning and how they have emotionally learned to live with the disease. And we need to all push more in that direction to share that part of our stories as well.

David:

I'm a big believer in helping is healing.

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The Arthritis Foundation couldn't do awesome things without your support. Your donation fuels our powerful movement to advance arthritis research and resources, like this podcast and much more. Every dollar makes a difference. Give a gift now at <u>https://www.arthritis.org/donate</u>.

Rebecca:

We like to wrap up our conversation with you sharing your top three takeaways from our conversation about grief and chronic pain today. So, if you can share those with us, David.

David:

Sure. Grief is organic. It's part of life. I think a second one would be: Become your own grief expert. And the third one would be: It's important that you fully understand your life, even if no one else gets it.

Rebecca:

Courtney, we've been able to have this conversation finally. What are your takeaways?

Courtney:

Grief is in the heart and that comparison is in the mind. And as a person who tries to think a lot and overthinks a lot, I really do need that reminder to sometimes drop down and get into my body and out of my head. So, I really appreciate that. And then



similarly, that meaning is not in the diagnosis, but that it is in how we respond after that and what we do with that diagnosis.

And that's gonna be very helpful in working with the people that I do, because they do struggle with that idea of finding meaning in their diagnosis. And then also the idea that we may not come out of grief and have to learn to live with it. And I really appreciated the numerous times that David said "and" in this conversation — because that is what so many of us are thinking: it's black or white, it's that side or that side — and really life is all gray and we have to live with all of it.

Rebecca:

In that pause that you give too, when you're answering a question: That's the pause that I think we all rush through life and we don't get, taking that pause and waiting for the rest, right? Thank you so much, David Kessler, for joining us on this episode.

David: Thank you.

Rebecca:

Courtney, I'm so happy we could shine a light on grief and chronic pain for our listeners. Just a reminder to everybody listening that we do have our app called Vim, and we actually had an emotional well-being quest that you could do: a six-week guide to helping you address your emotional well-being.

Check out the podcast episode, if you haven't listened to it already, that Courtney and I did at the beginning of this year, called "Making Mental Health a Priority." We'll definitely have some resources for David Kessler's books and his website in our show notes. So, check it out at arthritis.org/podcast. Thanks everyone. Thanks, David. Thanks, Courtney.

David: Thank you all so much, take care.

Courtney: Thank you.

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