

## Podcast 351 Gray Transcript

Karen Wyatt: Today, I'm very happy to welcome my guest Dianne Gray. Dianne has been a death doula for over 30 years. She is a grief specialist and the Chief Innovation and Patient Advocacy Officer at Acclivity Health. Dianne is a self-proclaimed “survivor and thriver” following the 10 year caregiving, palliative care, and hospice journey with her son Austin, who died in 2005 from a rare neurodegenerative disorder. Following her son's death, Dianne has dedicated her life to improving care for all adults and children facing serious illness. She believes that death and grief are a part of the wellness movement and today we're going to talk all about that; all about death and grief and how they belong in life and in wellness. So Dianne, welcome and thank you so much for joining me today.

Dianne Gray: Thanks for having me, I'm honored to be here. I've followed your work for a while, and you've spoken to so many people that I know and I work with. So this is great. Thank you.

Karen Wyatt: Yeah, well I'm really interested to hear your story. And from your bio, you refer to your journey as “surviving and thriving” after - what I just have to say - has to be every parent's worst possible nightmare. And so I would appreciate it if you would just talk a little bit about the surviving and the thriving, and how you managed that in that entire process.

Dianne Gray: Ah, I think of it as, you know - to quote someone else's very famous book - it was the best of times and it was the worst of times, right? And I think that, like many people, we get a diagnosis, and you know in my son's case, he was given the diagnosis when I was 30 years old. And I was told he had retinitis pigmentosa, which, because I had studied it in college - I studied sports medicine, sports management and was fascinated by neurology, of all things, and not much else. But I learned about retinitis pigmentosa, and my son would fall down all the time. Took him to several doctors; the first pediatrician said, get him out of those Keds. You're an over-reactive first time mom. I was like, oh my gosh, maybe I am. No - three years later through spinal taps, many tests, the fabulous Dr. Bascom Palmer told us that he had retinitis pigmentosa, but that was the tip of the iceberg. A year and a half later, we found out that he had a rare one in a million - statistically one in a million - neurological disorder called NBIA Disorder. And the short of it is that it's in the basal ganglia. I had studied that in college. I knew what was going on. And long story short, they told me that his prognosis was that he would have at most two years to live, which meant that he would die when he was six, turning seven. But that's not what happened. Austin actually lived until he was 14. We made some great decisions and in hindsight, we made some not so great decisions. I lost my marriage, my home. I lost everything and yet gained everything. And Austin died in 2005. Unfortunately, you know, he stopped walking the last five years of his life. He stopped eating, swallowing, and talking between the ages of 9 and 14. He was in bed for five years. We had at-home hospice. The pediatric palliative care and pediatric hospice regs are different, as you know, than adults. They can be on hospice, kids can, for long periods of time. Austin was on morphine, methadone, phenobarb, baclofen, Ativan around the clock because his specific disease causes intractable pain and suffering. Most

physicians say that they never ever want another child with that disorder. Please don't refer them to me even though they feel great empathy and sympathy and compassion certainly. Austin suffered in four-hour cycles of excruciating pain that the morphine just didn't touch. And they were sure that we were gonna, you know, something was gonna happen and that the medication would kill him. It didn't. So the short version is that Austin was injured by - not one of our regular team nurses through hospice - we had a visiting nurse because there is a shortage of pediatric hospice and palliative care nurses in our country. And the nurse turned him and caused an injury that we could not find through traditional diagnostics. And it was determined then that Austin was also dying. And so through hospice's help we removed nutrition and hydration and that lasted 18 days. And Austin died peacefully in February of 2005.

Karen Wyatt: Oh my gosh, wow. So on that journey you became really an expert, in so many ways, in caregiving but also in loss - continual loss - and anticipatory grief, I'm sure. And then dealing with all of the grief experience afterwards, after his death.

Dianne Gray: Sure. I mean, I think also... and I have to credit my mom for teaching us this that you know, life is often a two-sided coin and through faith we know that there's dark and light. These coins - there's the heads and the tails. I mean, yes, it was a wretched, wretched experience. I mean, seriously? I mean, poop flying off the bed and - you know this as a doctor - you know, dying is hard work when the body is struggling to live and struggling to die and fighting itself constantly. There's always an orifice that has something going on. And sometimes all at the same time. You see the best in people, you see the worst in people. The people you think that will be there for you can't handle it. Don't show up. Can't be bothered. Can't face pain. Can't face suffering. It looks like their child. It reminds them of something. Or the people you least expect show up as like your neighbor next door. We had a doctor who moved in next door. She was a podiatrist, but she would come and do her charts at 4:30 AM so I could sleep between 4:30 and 7:30 AM. So I got three hours of solid sleep for a couple nights a week because we didn't have care often, especially ages 0-10, you know. And Austin was cerebral, he was cognitively intact. He understood what was going on including the day he died. I told him that, I need you to go, I need you to go... For our family - this is my family's language, and not to be disrespectful to anyone else - but you know, for our family's language I said, Jesus is waiting and I want you to go to Jesus. You've been a good boy and a good son and a good brother. So I want you to go. I will carry the pain of missing you, you go now. And he looked at me like... and we had this communication between us because he couldn't speak the last few years because of, you know, everything. And his muscles were just not working. But with that said, he could smile and he could blink. So I told him, it's time. I'm deciding for us because what about what little boys want to do? They want to protect mommy and they want to stay with mommy. So we made some tough decisions and he died beautifully.

Karen Wyatt: Wow. And from the work that you're doing now, it's clear to me that you utilized, over time, the pain of all of that journey to kind of transform it into your ability to help others because you know what this path is like and you know the pain and

suffering on the path. So were you called to start working with other people who were dying right away after his death or what was that experience like?

Dianne Gray: Well, oddly my dad died when he was 39 and I was 9. So I started learning and studying the work of Elizabeth Kubler Ross when I was like 9 and 10 years old. My dad died in the early seventies. So that's about the time that *On Death and Dying* came out and Medicare benefits started and, you know, all of these other things; the hospice benefit and all of these other things were unfolding. And that's the time where we also started this language about connection between here and there. And I have to credit my mom who said, your dad will always be with you. He is always around you. He is here. There are some other things she didn't do - like take us to the funeral, which caused its own therapy sessions.

Karen Wyatt: But normal for the times we were in.

Dianne Gray: Yeah. I want to be your friend and you make the decision and all that. But I think quite honestly in hindsight - so back to your question - is that I think I've always been in this line of work. So that's why, in college, I started helping people who were gonna die. Like I was 19 years old and I remember this girl was in a car accident when I was a little girl. I was 12 and she died in the car in front of my grandmother's house, and I ran to the car and everybody else ran away. So I think in some way I've always been this person. My dad died. He visited me when I was 14 and told me it was gonna be okay. I felt at peace ever since. So in college when there was a suicide on my floor, I ran in and the rest of the screaming girls on my floor ran out. And death is not the enemy, suffering is the enemy. If there's an enemy, suffering is - physical suffering.

Karen Wyatt: Exactly. And so it sounds like this has been your path, really, and you've followed it. You've been willing to follow it and willing to do what is before you, it sounds like - stepping out and helping the people who come across your path who need your help.

Dianne Gray: Yes and no, quite honestly. Because I remember my best friend, when Austin died, my best friend said - we walked in one night after the movies - and she said to me, what are you gonna do now? And I was like sobbing and I said, I'm going to lay down on the sidewalk in front of my house and never get up. And so then someone from Harvard asked me if I would do a case study with them at a presentation - bioethics, right, because of my path. And I said sure, but I'm going to go back to my other life after that. And then somebody connected me to some committee and someone else connected me to the Children's Hospice and Palliative Care Network and they said, will you be on our board? And I said yeah, sure, but I'm going to go back to my other life right? Because that was you know, I've had it. And that was in 2005. So here I am still, you know?

Karen Wyatt: Here you are today – not going back yet.

Dianne Gray: I mean I had an opportunity in 2018 to go in a completely different place doing social emotional learning for children all over the world and running a foundation.

And Jeremy Powell with Acclivity Health Solutions showed up at my house in Nashville knocking on the door saying, but I want you to come work with me. And I said no, I think I'm finally out of the hospital field and I'm onto this next chapter. And he said no, no, no, no. And I said, no, I started my job - I'm starting a job on Monday. And he said, I just need to talk to you for five hours. And sure enough, by the end of the talk, I said, you know what? I'm still in, and so here I am.

But to be clear, it's not the life experience - the life experience informs my empathy and compassion. But I've also taken a gazillion courses in Long Beach through what was the... There was a panel... "IPC" [?] back in the whatever, 2000's, you know. I did IPC panels. I took classes on pain management. I did go to college and studied, you know, the nervous system and pathways in the brain and every anatomy, phys, kines, premed, and have taken a bunch of courses on grief work and grief specialist classes, and became a certified death doula or end-of-life doula, and taken courses on communication and end-of-life. And you know, so I think that's as important. And just the personal part informs the empathy and compassion, if that makes sense.

Karen Wyatt: Yes. So, you have the experience and the wisdom of your experience, but you've added a lot of knowledge to it by intentionally seeking out training and teaching to learn what else you needed to know, which makes a lot of sense. And one thing in your bio that I really liked is the statement that death and grief are a part of the wellness movement. And I love hearing that because I have an issue that, many times, I don't hear that coming from the wellness movement. In fact, I sometimes hear wellness coaches who are afraid of talking about grief and afraid of the subject of death. And I feel that we do such a disservice if we leave that out. As you said, it's the other side of the coin. It's half of our existence. It's part of the cycle of life. And so, talk a little bit more about what that means to you and how we can do a better job of incorporating death into the wellness movement.

Dianne Gray: Sure. So Elizabeth Kubler Ross wrote this phenomenal document called The Dougy Letter, handwritten in markers a long time ago. A little boy named Dougy wrote to Elizabeth and said, why is there death and why do children die? And she basically wrote this beautiful document and said, just as life is about circles and seasons and, you know, a ship may go from our sight but it doesn't disappear, right? So if you look at the concept of a quadrant, we're intellectual, emotional, physical and spiritual beings, basically. So when we say that there is death as part of wellness it's that, first of all, my experience is when people finally make those plans and create a will or a living will or they decide upon a healthcare proxy, even if the rest of the family is angry about it, you know, they acknowledge the wholeness within themselves. They acknowledge birth and rebirth. If we don't you want to use the "D word," you know if a person is a Christian, I use death as a rebirth. Why? Because it's a birth into the next chapter of your soul if you're a Christian. The Buddhists believe in reincarnation. You know, we could just go on and on down that. But also, cells - our cellular structure was created to disintegrate. There are cells that don't regenerate, that's science - microscope, like let's look at it on a slide. Some live, some die. When they die, they're done. You know? It is the way it is. We'll never have another, you know, April 13, 2022 at whatever time this is

right? We won't, we won't. This is it. The minute dies. So when we start accepting that, we grow to appreciate life, breath, even pain, even suffering. We start to integrate meaning, which is the work of Viktor Frankl in logotherapy. So it's nonsensical to me to say that beauty, joy, all these lovely things, but we don't want pain, we don't want suffering. We don't want that. We don't want death. We don't want grief. Because if you look at the work, the beautiful work of Khalil Gibran, your joy is your sorrow. That's wholeness; that's wellness, that's acceptance. That's making peace with the totality of the experience, and then watch out. Then look and see who one can become. But I find that when we don't acknowledge the entirety of our existence, we're really living only to a certain extent or percentage of our capacity because we're not allowing for this.

Karen Wyatt: It's so true. We can't be whole if we're in denial of this part of our existence. That is true, universally true. Everything in the universe dies that is material. And so we can't possibly be whole if we're shutting that out of our awareness and using up our energy just to deny that truth and that fact that we will die one day. It's such a waste of our time and our energy to deny what's true and even denying the most essential part of our humanity in a way.

Dianne Gray: Well, that's right. And I mean, I find too... So as a death doula, I do death doula work a little bit differently - I work virtually. I almost never meet my clients. I speak with them from - maybe I have a six month time limit basically. Um, and that's intentional. I'm not there as a crutch. I'm there to help inform and lead and mentor kind of like Alan Wolfelt companioning - I will walk alongside, right? I do help bedside in some sense, you know, this is the era of Covid, right? So a lot has changed, but I found that the people who go through the dying process with more grace and peace are those people that have come to at least an acceptance that life is finite. Life as we know it on the planet, standing, walking being in this... You know, and that doesn't have to do with religion. That's just that they come to an understanding that cells were designed to only live for a certain period of time and that's how it is right now.

Karen Wyatt: And I found too that, well, some people come to their dying process already aware of how finite life is. But in my experience, a lot of people have this awakening when they receive a terminal diagnosis or as they are approaching the end of life and it becomes real to them finally. And I don't know if you've seen that in your work, but that's when people start to begin to grow a bit at the very end of life.

Dianne Gray: It's beautiful. I call it that they blossom, right? Elizabeth Kubler Ross used to say that people pop. That's where they get to this part where all of a sudden there's an illumination. They say things and they become people that they never expected to be. Even Elizabeth Kubler Ross quite honestly was, you know, I want to die, I wanna die, I wanna die for nine years. She had a series of strokes and at the end she said, huh, okay, I kinda get it now. People are going to like, they're going to care for me too. And, it's okay. I might want to stick around for a little bit here. And that's when she died, right? Because of this peace that came from the situation for her.

Karen Wyatt: Yeah. And this role reversal in a way of having to be the patient and allow other people to give to her and take care of her after so much work that she had done for her lifetime for others.

Dianne Gray: Absolutely.

Karen Wyatt: We were talking a little bit about the work of Elizabeth Kubler Ross and I know that you mentioned that that's been helpful to you for a long time, even before your son died or before you knew that you were on this journey. But I was curious to know if there were any other tools that have been helpful to you as part of your grief process or other things you've used to help you grow and deal with grief.

Dianne Gray: Oh sure. Um well, first of all... So I'm on the board of the Elizabeth Kubler Ross Foundation. So if you look at the fact that I'm some skinny kid from Boca Raton, Florida who now lives on the west coast of Florida and ended up on the board of Elizabeth Kubler Ross Foundation, the first tool in my toolbox for grief was to imagine that anything is possible. That I might have lived through this life journey, but it also broke me open and prepared me for wondrous things. I think that the universe or for me, God, it's not just about how this bad thing happened and then all these other bad things are gonna happen. It also prepared me that, yes, just as I had a child with a rare one in a million disease and you might know somebody that died as a result of X, amazing other things could happen. Like the fact that you're doing a podcast now, right? Neither of us are in our twenties and here we are. And who knows what the next adventure is and the next adventure. And what it did was, you know, this whole concept of being open to the adventure versus always looking for the gloom and doom is based on fabulous research on resilience. And you know, we know that being resilient depends upon a few things.

First of all, I exercised through my grief. Okay, it was mighty tempting to lay on the couch and not move for the rest of my life. But when I one day woke up and I thought, oh gosh - actually it was an expletive - you know, how I grieve is on me. Great, that's the truth of the matter. How I grieved was on me. I couldn't change the fact that I was grieving because the death obviously happened. And not just the death, the 14 years before. But that it was on me how I was going to get through it, and it's just basic science. Endorphins. I exercised, I felt better, period. Full stop. Okay. Did I want to feel better or did I want to feel horrible? Yeah, there were days I wanted to feel horrible. So I stayed in bed and watched Hallmark and got up and got to work and came home and took care of myself, had hot tea. And the more I drink alcohol, that was science. Okay. You want to be depressed, you drink. You don't want to be depressed, don't drink. It's really not at all... Well the reason I'm making it sound kind of like that is that the emotions were so big. Grief is hard, grief is ugly, it is messy. I yelled at the water department lady, I'll never forget it. Why is my water shut off? She said ma'am, you didn't pay your bill. And yes I did. And I went back in the file and I had not paid the bill. Why? Because I left my passport in the freezer. I ran my bike into something. Grief makes your brain into scrambled eggs sometimes. And so I needed to figure out like, okay, I am not doing this this way. So exercise - what I put in my body was important, healthy food. I listen to music all the time. For me, it was Steven Curtis Chapman's music all the time - just while

I was exercising. And now Stanford has research as of, whatever year that was, that shows that music and being in nature is healing - exercise, music, nature, four things... water. My buddy J. Nichols, Wallace J. Nichols wrote a beautiful book called Blue Mind, and it talks about being in, on, near, around the water is healing, shows up on a functional MRI. So I incorporated that. You know, all these things were really helpful. The people who were toxic - I call them the energy vampires - the people who were just like, oh ohhh. I love you, but I don't have time some days for that. My daughter and I used to go to the grocery store and people would walk up - we live in a fairly smaller community - and we would go to Publix and people would walk up, oh my gosh, she looks so tired. She would look at me and I would look at her and we would be like, I thought we were doing pretty good today.

Karen Wyatt: Thanks for telling me, I look tired. Great.

Dianne Gray: Yeah, I'm tired, what do you think? I think that the thing was we were actually doing okay on that day, and that's not to say... People just don't know what to say sometimes. So instead of getting mad at them, you know, I learned that people just by and large, nobody knows what to say. We all just do the best we can on any given day and that most people don't wake up looking to ruin someone else's life, you know? So that was my basic toolbox.

Karen Wyatt: And I like that they're simple tools because for one thing, you're not in a frame of mind to do anything very complicated or that has a lot of steps to it. It's like, it's simple - go outside, go for a walk, be near water, listen to some music. And you just repeat those things over and over every day as you're working your way through.

Dianne Gray: So I also was blessed though to meet some great therapists. And one or two who are really not great therapists. And it's just ludicrous. And I think, you know... What I tell people as a grief specialist is look, I apply the philosophy of be a good neighbor, the good spirit. And the reason that I apply that is that you're not gonna like every neighbor, you're not gonna like every friend, you're not going to connect with every person. So anyway, the gist of it is that we try... You know, therapists may not all fit with everyone. So go to the next person. It doesn't mean that therapy is bad. Therapy works for some people. It doesn't work for others.

Karen Wyatt: And just as in everything, you know, as you were saying, you will resonate more with certain people than you do with other people. So we just have to find those people that are on our wavelength.

Dianne Gray: Absolutely. So it's not to diminish the things that do cost money. Like I do believe in therapy. And I did end up having a great therapist who at least listened to me and my sobbing years. But one of the people that I met, Dr Gloria Horsley, she really, she's a part of the Open to Hope Foundation. She changed my life forever basically. She used to call me on Sunday night, which used to irritate the hay out of me during those years because Sunday was family day in my life - and it always had been when my kids were little and my son was alive. Sunday was family day. It was family time, and it was

personal time, and I was in my home. But Gloria used to call me at 9:30 on a Sunday night. It just used to frost me for the longest time until I realized that the reason it used to bother me so much was that I was alone on family day, and I was alone on family night. And that I didn't have anybody. But Gloria always made sure to call me on Sunday night. And she had lost her son in a tragic accident years and years prior. And I remember telling her, I want to volunteer for hospice and I wanted... One of my passions is medical ethics and I said, I want to do that. And she said, no. I said, what do you mean, no? I'm trained and... blah blah blah. She said, give it a few years. And I said, well just how long is this grief journey going to last? And she said, seven years. She said, think about it in the context of seven years. I was like, why would you ever tell me that? That's so far away. But she was being honest with me. And she said, because it's a path, the journey, it's not, you know, flip the switch thing. She said, it takes years and years and years of working through your emotions. She said, of course you're gonna laugh again. Which I did - year three I had this laugh out loud, and I almost looked around like who was that? Because it was one of those from-the-gut laughs. And I thought of Gloria on that day. Then came year five; I felt like myself. And year seven, I was fully integrated. Not with myself but who I had become. And I came to peace with the fact that I had to also mourn who I was, and I would never have her back again. I was never going to be my daughter's mother the way that I was ever again. And she needed to mourn that too.

Karen Wyatt: Mmmm that's really beautiful that you say that because I look back and... I don't know if you know this, but my father died by suicide many, many years ago, which was really the catalyst for my journey into becoming a hospice doctor. But during the early years of my grief process, I would wake up everyday thinking, someday I'll wake up in the morning and I'm going to be who I was before he died. I'm going to feel like I used to feel. And I was hanging on to that idea and I wanted... I wanted to go backwards and be who I was before. And it wasn't until I got on hospice and started sitting with patients who were dealing with life-limiting illness and families who were experiencing grief that I realized I wasn't going back. Just as you were saying, it finally hit me. And that actually, I thought, but of course an event like this in your life is meant to change you. It's meant to change who you are. It's meant to shift your path and open you and actually help you become more of who you truly are. I look at it now, that's how I see it. But, so you experienced that too, it sounds like.

Dianne Gray: I did, but also Karen... I think it's fascinating. So we, in the grieving, or those that are helping someone die, you know, nobody else is staying the same either. I separated myself out as though I was different from them. And meanwhile my next door neighbor wasn't staying the same. She had another baby. She...you know, her husband cheated on her. So she was going through her things. You know, my neighbor on the other side was going through her things. She wasn't the same. So none of us are the same. Anyway, I just was in my little bubble thinking that I was going to stay... I was mourning. And I think the more we can teach people that life is about change, period. Full stop. Get in the river, jump in because the river's going anyway and you can either try and hold onto the rock for the next five years or you can float down the river and start to see where you're going. I think we do kids and children a disservice. I mean, I've written grief books for kids and things like that. And the thing that I've learned when you

talk to kids... They kind of, sort of, they might miss their doggy or their kitty or their bird or whatever, dad or mom. But they kind of, sort of get back in the river. But we, as adults, we don't do such a great job of that, I think.

Karen Wyatt: It's true. And you said something earlier about staying open to whatever happens and whatever comes your way. And I think about staying curious like, oh, isn't this interesting that this is happening now? You know, how fascinating is life? The things that end up occurring and the people we meet and the events that happen to us that we never could have predicted or imagined.

Dianne Gray: I'll tell you - true story - just happened two weeks ago. I went to the opening of a grief center for children here in Naples. And I sit down at the table, and I was exhausted. And it said, you know, table one. And I was like, it's in the front. We've all done that. We've all had to go to events when we're over-tired. I said, ok, ok, I got this. I sit down at the only seat, and I'm seated next to this guy. I was like, oh that's nice and you know, conversing and yada yada. He said, hey, let's go - while we're at table one - let's go get some food. Okay, that's fine. So we're in line. And this song comes on by Brian Mcknight. And I said, oh I love that song. It's one of my favorites. And he says, yeah, Brian Mcknight. He said, I know his drummer. The guy says, I know his drummer. I said really? He said, yeah. I said, that's funny - I know his drummer. And he looked at me... Now I'm in Naples. This is somebody I know from LA. And he said, Prescott. I said, yeah, Prescott Ellison. He said, yeah, how do you know so and so?

Okay, we're talking, we get back to the table. We sit down, I pick up the phone. I called Prescott Ellison. He's texting Prescott Ellison, who has a super cool - it's called Superfoods, which is about kids and nutrition. But he used to be Brian Mcknight's drummer. And we start talking about how in this great big world of ours we come to find out that this particular person's dad has a very serious illness - autoimmune disease - had not gotten great care or information from his PCP, didn't get a prescription for a fungus - and you know where that's gonna go. And he's had the fungal infection for a long time. And he said, hey, I can't believe this, but maybe you could help with my dad. And I said, all right, sure. Let me see what I can do. Let me talk to your dad. You see what I'm saying? You have the PCP. The next day the PCP calls in the prescription after not doing it for weeks and weeks and weeks on end. Dad's on the antifungal, you know, etcetera. Call NORD - National Organization of Rare Disorders. How would I have known about that? Well, because my son had a rare disorder. I wrote an article with NORD for the AAP. NORD says, hey, we have some of the best specific autoimmune disease doctors actually in south Florida at these two locations. Here are their numbers. The dad is now connected with these two amazing physicians in Tampa that are part of this network of doctors. But that's how I think it works. If I stop to look at, oh woe is me, my son died and that's the end of my life. No, it's not. It's not at all. It's that I go to some event, and you go to an event or you talk to someone or somebody listening to this says, oh my gosh, I met so and so in the grocery store. Or my car broke down on the corner of X, but I met person Y. And I have the secret sauce to help them with this one little part of their life. Maybe they just needed a smile. Maybe they needed the door opening. Elizabeth Kubler Ross gave a talk in Australia and was there doing the Q and A afterward. And this

flight attendant went back to her hotel where Ken Ross, Elizabeth's son, was staying in the hotel. And she called Elizabeth's room and Ken answered the phone because Elizabeth hadn't returned yet. And she was a flight attendant and she said hi, my name is so and so. And I just went to see your mother talk at this lecture hall in Australia in Sydney. And she said, I just want to tell you that I was going to kill myself. But I went to hear... Yeah, it makes me tear up, true story. I went to hear your mom talk, and she said that every life has meaning and that we need to search for the meaning and the purpose. And she said, so when I got back and I had listened to your mom, and I got back into my room there was a butterfly inside my hotel room with all the doors closed and all the windows closed and I can't explain it. But I took that as a sign that I need to dedicate my life to human service. And she became a hospice volunteer.

Karen Wyatt: Wow, wow, that gives me goosebumps.

Dianne Gray: Oh your life, Karen, your experience, your podcast, your work, the people you talk to, the people who are listening. It's all connected in some way. I know it's true. I hear these stories every day of my life. And the what and how to do with it, you know, what do we do with it all requires listening as much as it does talking.

Karen Wyatt: Yeah, it's so true. I had something similar happen speaking at an event in St. Louis and meeting some people there, including this amazing hospice nurse. And then randomly two weeks later getting a phone call from someone in Minnesota who ends up telling me her brother is in St. Louis needing hospice care and hasn't been able to get anyone to refer him for hospice care. Oh but I just met this amazing nurse. So you know it's very similar. I was able to connect them. He got on hospice care immediately. But who knew any of that could possibly happen? And you're right, we do have to pay attention, we have to listen, we have to engage with people and hear their stories and then retain some of that information to help us so that we can be a good conduit for these connections. But I really feel like it's all around us. It's everywhere. We're always, you know, at the nexus of some synapses and connections that are forming all around us when we just pay attention.

Dianne Gray: Absolutely. And ask people... I mean it's a really strange thing that we're going through right now over the last few years with Covid. You know, sequester, stay to yourself, stay isolated, etcetera. But that doesn't mean that we can't interact. Doesn't mean that we can't just send a text and say, thinking about you today, how's your life? I mean we can still do it. It's not as fun for sure. But we can still engage and interact, right?

Karen Wyatt: Yeah, definitely. And I was curious because in the bullet points I received of things we could talk about, one of the points was how social media helped you with your grieving process. And I think about that all the time that our social media is another part of our networking. We don't always use it in positive ways. But I was curious to know your take on that.

Dianne Gray: Great question. And when I do these podcasts, that's one of my favorite questions because I truly feel that we can have a polarized view of media. Many people

say it's all bad, it's all good. But it's just like most everything else. You know, in moderation, right? So first of all your grief is about choice. You want to go down the rabbit hole. One wants to go down the rabbit hole and one wants to be a part of an angry victimized mentality - go for it. There are plenty of groups that do that. I just got tired of it after a while. And I had this message in my ear - true story. I woke up on January 4th of 2007. And for me, I heard God tell me, go and be sad no more. And regardless of whether I heard that from like God's talking to me or my own whatever, right? That's what I heard. And I thought about it and it was like oh my gosh, I have some responsibility in my own grief journey. Social media is important because we are visual. 80% of us are visual kinesthetic learners. That's the research. 20% of us are auditory learners. So if we're paying attention and we get into that, you know, energy suck of social media and all we're seeing is angry people and angry people and angry people, then who do we become? We become that. The other thing about social media that's super important is this: many, if not most, people are not trained to be empathetic, compassionate individuals and say, oh I'm sorry. Oh that must be so difficult. Oh you must be going through a hard time. Is there anything... or how about if I... So what do they do? They get on social media and they say, oh I lost my dog too. That does not help. Doesn't help. What does help is providing a response to the person's tragic situation. If your response is energy based, I send you love and light. If you're faith-based, holding you in prayer. It must - for empathy and compassion - it must be so difficult to experience this. I'm so sorry that you're going through this. Something about the other person. But please, for God's sakes, I wish someone would put out a memo that says do not respond with your own personal worst story. Like that doesn't do anybody any good. Well, I thought they might like to hear about me. That doesn't help the person. So yes, social media can be positive because there's great content right now on instagram, on EMDR, on grief, on resources, on psychotherapy. But again, buyer beware. There's also some real bad stuff out there. You know, people who just are looking to polarize and make people angry and let your gut drive you, you know, and shut that off. And also at the same time the great thing about social media is that it's available at 3 a.m. And grieving people can't sleep. I don't know about you, but I didn't. When your dad, you know, completed suicide did you sleep? Probably not.

Karen Wyatt: No, no, definitely not. And I do remember. When my mom was dying and I was taking care of her, I just, I remember at night laying awake and scrolling through the phone. And how just so often I would find exactly the right article or post somehow on social media that someone shared. And I realized something you were talking about - how we're responsible for what we consume - and that includes media. You know, we're responsible to be careful about that and to look for those positive things that will nourish us, and just scroll right past and move right beyond anything that's negative and hateful and will suck our energy away from us.

Dianne Gray: It's true. On the positive side though, too, I think we're at a unique time when technology can be our friend. Now we have to be mindful that technology impacts our brains. So here's an example. So if you look at... Like I have something on my phone and my watch that says, okay, here's your usage of social media, right? So it's important to be mindful of that because social media can be, it can hit your dopamine receptors in

your brain and say more and more and more and more and more. So if we're not mindful of our consumption, just like anything else, we can get on the wrong end of that. But with that said there's some great apps.

So I'd like to talk about apps real quick. Calm app is phenomenal, phenomenal. I like the water app. Some people like the fire in it. Some people like the meditation. It's a great app. The other thing is the tapping app. So tapping you'll see sometimes in the sponsored ads, right? It works. It's neuroscience. It actually works to reduce anxiety, helps improve sleep. I had a client called me last night late - a grief client whose mother completed suicide. And you know, I introduced him to the app and he said, I fell asleep, I fell asleep while I was doing the app. You know, so the technology is not the enemy. Technology can be amazingly helpful just like... You know, so I work for Acclivity Health Solutions. And you know in my life too, and they're a data analytics company. And we can use AI and machine learning and claims based data to do prognostication and help hospitals and hospices and PCP, you know, primary care providers understand when their patients are palliative care or hospice eligible.

Karen Wyatt: Which is amazing. Which is a huge breakthrough since that's one of our major issues in hospice care is not getting people admitted early enough in the course of their illness.

Dianne Gray: What I think that Acclivity also does and attack is it helps doctors that are on the fence. Well I don't know, I really don't want Mrs. Smith to go to hospice, or I'll just take care of her myself. It shows people, you know, hello this is her frailty and meds and all of these other things. And you know I want to give you a real life example really quickly of what not having that looks like. And you've seen this a lot. So in closing, I got a referral as an end of life doula. The family called me and they just didn't know what they wanted or needed but they got my name because I had helped somebody who's a celebrity. And I did a podcast for that person and she said that I had helped her with her mother's passing, which I did. So this person called me and said, you know my husband is 48 years old. And we've been asking our oncologist for a prognosis. They didn't use that word. But that's what they were asking; what do we expect? What's going to happen? Is my husband going to live? And he's down to 98 pounds. And I said well when is your next appointment? And they said it's actually tomorrow. And I said well why don't you ask your oncologist at a major city, major medical institution? Very well regarded, a very well regarded oncologist. Why don't you ask him if I can act as your trained patient advocate, patient navigator? Okay that would be wonderful. I said, ask him if you can facetime me into your thing. I'll sign whatever forms you need to sign, and we'll do it that way. So the family gets in there and no kidding. The wife is 43, the husband's 48. And they asked three times for prognosis. The first time the physician says - and again, with compassion and kindness. I'm not painting a picture that he's not compassionate, he's compassionate. He says, well are you sure you want to know now? I'm on my little phone here on facetime. And then the second time, are you sure? And the wife says, I'm sure. And I said, Dr. so and so would you like to speak with the patient himself - who was not able to eat? Etcetera etcetera. He'd been living in a rehabilitation center in a different part of New York and he had him come in by ambulance. And the father of the dad said I want

to know when can I start my next round of treatment. I just need to eat some more. And the doctor said, ``So you really want to know your prognosis?'' a third time. I about lost my mind. And I said Dr. so and so, this is the part where I'm gonna just interject for a minute. I said, they have a three year old and an eight year old. It is Thursday afternoon. He came in here by ambulance; he wants to know what to expect. You're the physician; you are the most trained person in the room. You have his records. I don't have his records. I'm acting as a communication facilitator here. That's it. I'm a non-medical professional. He's asking you to give him the information so he can make plans for his family. And I said, so please tell them something. He says for real, no kidding, I should have told you at last month's appointment that you had days to weeks to live. Major major major metropolitan medical center in New York City. And there was silence, and I said, so how would you like to proceed from here, Dr so and so? And he says, well maybe you can advise them. Bleeping kidding me?! I said, I can. But you're the physician. What would you like to suggest to them? Nothing came out of that man's mouth for 10 seconds, 15 seconds, 20 seconds. And finally I said, how about a palliative care consult? Because you and I know right? I mean you don't want to say, oh you're thinking you're coming in for treatment and then you're gonna tell them he's going to go on hospice in five seconds. So he says to him, well I think that's a great idea. I can get you a palliative care consult in two hours. Family waits. I call. And he said, by the way, I do think you're going to die in a couple of days.

Karen Wyatt: Oh my gosh.

Dianne Gray: I did a hospice referral myself because you can do that. I called the hospice that was down the street from their house. The guy went home, went straight into hospice on Thursday night and died on Tuesday. The brothers all flew in over the weekend. Kids were as prepared as anyone can be with having three days notice that daddy's gonna die. And there it is. That's why I do these podcasts. That's why I work for the company I work for. It's despicable to me, and I could repeat that story using different cities, different doctors, different patients. And so could you. I find it despicable.

Karen Wyatt: Yeah. I was going to say that as well. That happens over and over again. And it's so tragic when we have palliative care available that could have been started at any time, any time in the course of that patient's treatment so that he's receiving the emotional, psychological, spiritual support that he and the family need to go through this process.

Dianne Gray: Or his wife could. Or he wouldn't have left the family \$30,000 in debt, which is the text I got from that family yesterday. I mean, it just is mind boggling. And so that's why I do these. And I wouldn't have known about the insurance reimbursement and all the protocols and all the pain management and all of how to navigate the system unless I went through all that mess for 12 to 14 years with my son, you know.

Karen Wyatt: Yeah. Yeah. So you have the gift of experience that tells you what you need to know to be helpful to people. But we have this major gap that we're working on

within the medical system itself with physicians. But as you say, the data Acclivity is producing should be helpful as we try to educate the medical system.

Dianne Gray: It is, and I think there are a lot of things - and I want to be clear about this real quick, with physicians - they're not the enemy. They're - by and large - kind, compassionate, empathetic professionals who received less than one hour of training on how to have end-of-life communications with patients and families. They also are human beings and their own family members have died, or they have children at home, or they have their own families, and they don't want to be the one to tell somebody that quote "bad news." But I think that's starting to change. I think the shift is slow, agonizingly slow. But I do think that, with the emergence of companies like Acclivity, that you do have the analytics that helps prepare doctors and back it up. So that when they think that, maybe it's right there in their face if they use it, they can help transition them to hospice and palliative care, which the research shows provides comfort and may be a longer life by a couple of months.

Karen Wyatt: Exactly and helps their loved ones with the grief process as well. Just to come full circle back to grief again. It all makes sense. As you said right at the beginning about incorporating death and grief into all of our wellness care, including in the medical system. That will change everything when we're able to do that.

Dianne Gray: I agree. And we look at right now. We look at the catastrophe that is our mental health and our mental well being. I call it mental wellness. So let's look at that in our country. So think about the fact that palliative care is available, which includes a social worker, grief, and bereavement care and so on and so on. So you have a family that can receive palliative care. Like even the family I told you about with the gentleman with the rare disease and the fungal infection. He has been eligible for palliative care for four years. Not on palliative care. I did a palliative consult, got him a palliative consult. But still, I'm just one little person somewhere. Someone should have said, sir, you are a 12 on the pain scale, for gosh sakes. Let's get you a palliative consult because your wife is going through this too. It's crazy.

Karen Wyatt: Yeah. Well Dianne, I appreciate what you're doing to make a difference, and that's how it begins. Each one of us. We do what we can and try to have our impact on the system and change things as we go. So I'm appreciative for the work you're doing. And then also for you taking the time to have this conversation because we're just spreading these seeds, I guess in the world.

Dianne Gray: Well thank you. You're doing great work. I've followed your podcast and I like the people that you've, you know, had on that I've seen so far, with Dr. Mulder and some others. And I think what you do is you blend humanity as in the crosshairs with medicine and that's a hard thing to find sometimes. So thank you. Thank you for your work and thanks for having me on today. I appreciate it.

Karen Wyatt: Thank you, Dianne. And good luck to you as you go forward in your work.

Dianne Gray: Thank you.