TODTAL DIGITAL #29:
Caregiving and Grief on Social Media



Guest: Mark J. Burkholder

Hosts: Caroline Eilbrecht, Dr. Jörg Noll, Dr. Simon Walter

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Transcript

00:00:08 Jörg

Welcome to our new episode of TODTAL DIGITAL.

In our podcast, we discuss digital ideas and developments in funeral culture and the funeral industry. We are Dr. Simon Walter from the Funeral Culture Foundation, or better known as the Stiftung Deutsche Bestattungskultur, and I'm Jörg Noll. Today, we'd like to introduce our new colleague, Caroline Eilbrecht, from the German Association for Funeral Directors, Bundesverband Deutscher Bestatter.

Hello, Caro. Hello, Simon.

00:00:39 Caro

Hello.

00:00:40 Simon

Hello, Jörg.

00:00:42 Jörg

Great to have you, but I'm more delighted even to say that we today have a special guest.

As you might have noticed, the episode is different. Our guest today is Mark Burkholder from the US, which is why the episode is in English. But don't worry, we will provide a translated transcript of this episode.

Welcome to TODTAL DIGITAL, Mark. Would you like to introduce yourself and briefly tell us what brought you here today?

00:01:11 Mark

Absolutely.

I'm very happy to be here. Thank you for making the switch to English for me.

So I was my wife Paige's caregiver for about four years. She was diagnosed with terminal cancer at the age of 32, right after we'd moved to a little island to kind of rebuild our life in Washington state here in the United States. And she was diagnosed with terminal cancer right after moving here. And I was by her side for those four years.

And after she passed away, I began posting essays and videos online, presenting the reality of being in a cancer battle and being a caregiver. And those videos have gone very wide and brought a lot of interesting opportunities into my life.

And I find myself sort of now being a voice for caregivers and people that are going through some of the lowest times in their life and trying to find a way to use that platform to connect other people facing that same isolation that I felt those years.

00:02:09 Caro

Yes, and just as a context, so you know how connected Mark is with everyone in a similar situation. He, as of today, has 103,000 followers on Instagram, about 4.5 million likes on TikTok, and his most-watched video has about 10.2 million views, which is over 83,000 hours [correction in transcript] of being watched.

And he also publishes articles and, as being said, has just launched his caregiver community.

00:02:44 Simon

So when we are thinking about cancer and someone battling cancer, I think many people would think about many different aspects of that experience, but not about documenting that time together and the aspect of caregiving that you talked about.

When did you and Paige decide in that situation between yourselves, “There is something happening here that we want to preserve for other people in whatever form”? What made you decide that together?

00:03:16 Mark

So we, after she was diagnosed, we would go online and we would see what other people were posting about cancer, about caregiving. And her cancer was terminal from day one. So we knew right from the get-go that she would not survive. And so much of the content, the videos, the accounts you see of cancer online, are people beating cancer. They show the highlights. They show the happy moments.

And it was very difficult to see all of that joy and celebration, knowing that we wouldn't get that. And so we began documenting through photo and video the process pretty early on. And our intention was to post it together throughout the journey. But we never ended up actually posting together. Whenever we tried to do it, we just either didn't feel right in the moment or just ran into the normal challenges of doing creative work together with a partner while also battling cancer.

And so I didn't end up posting my first video until the day that Paige lost consciousness. So the first video that I ever posted was the day after I ever got to speak to Paige for that last time. And that's just how it ended up being.

And as a result of our planning to do it, I have thousands of photos and videos, which I have cataloged and used to make the videos and content. So I'm very grateful to have that and that we did capture all of that, even though it is hard to work with much of the time.

00:04:53 Simon

When you accumulated all the documents, all the photos and the content, did you think ahead that, okay, we might have or I will have the opportunity to use that on social media in the way you do now, or did you also think about other media, or did you also think maybe a broad piece of that will also remain private for you as private memory?

00:05:16 Mark

It was a mix. Honestly, a lot of it was, I used the analogy of something like war photography, where, like, when you're going through something that's that intense, you just feel this urge to document it. And it just felt like something that I had to capture. And, you know, I'm a person that has always felt a need to share things that are powerful and impactful to me.

And I think by documenting it and taking those photos, it just sort of felt like I was, it felt like I was going through something so powerful and noteworthy. It just felt right at the time.

And when we were capturing them originally, we really didn't know what form it would take. You know, we thought that perhaps we would just start posting typical kind of day-to-day social media. “Here's what's happening.” But because it didn't end up happening until Paige passed away, it's taken the form it has now instead, which is a more video essays of me using all of those photos and videos.

But it's definitely evolved. I could never have pictured it becoming as large or growing as quickly as ended up happening.

00:06:33 Jörg

That actually backs the question, or let me introduce it a different way. On your first YouTube video, we saw many grateful comments, but also people who were concerned that you might feel some pressure to do it.

Did it ever feel like a burden to have to share the story to keep your promise to Paige?

00:06:50 Mark

It's something I think about a lot.

You know, it is not fun. It is not enjoyable work to sit down and put myself back into those years. But it feels important. It feels useful to others. It's clearly connecting with people. I think the hardest part for me, well, broadly, the answer to your question is yes. It has been very difficult in many ways. And that has changed. The ways it has been challenging has changed throughout this year, almost now, since Paige has passed away.

But the most difficult part is balancing my own need to rebuild and to grow and to continue on in my own life while still telling that story of Paige and I together in those years and navigating essentially two times. I'm doing all of this storytelling in one of the most challenging, probably the most challenging part of my timeline that I will ever live through, while also going through right now, today, an incredibly important period of rebuilding and healing. Figuring out how to do those side by side and what form it should take has been very challenging and has resulted in some starting and stopping of the process.

And right now, as we sort of record this, for the past few weeks, I've been, as I try to launch this community for caregivers, I'm going through the process right now of really thinking about, “What does this look like in the future?” How do I begin making that transition from just talking about those years themselves to beginning to keep telling the story, keep honoring Paige, but also looking forward at telling stories about rebuilding from grief, healing from grief, because those are the things that I need myself and in my own life.

00:08:54 Jörg

I think this is a very important aspect.

Before digging into that, I would like to ask you, how about parents, your family and friends, how did they react actually seeing those pictures and videos and hearing about the story after her passing?

00:09:11 Mark

It's been complicated. I think a lot of people in my life don't really know what to make of it.

The people that knew Paige really well and don't know me. It's hard. I mean, it's hard for a lot of those people to see. And if you were Paige's lifelong friend and you'd met me a few

times and you followed me on Instagram, and then all of a sudden now you're seeing very challenging things about the death of a close friend.

And in a strange way, I think the reaction that I get from people in my life tends to be either a little avoidant. They just find it challenging or strange to talk about or even sometimes a slight negative reaction. And yet the positive reaction online has been so large that it, numbers-wise, outweighs it.

But of course, in terms of the impact I feel in my day-to-day life, it's a strange balance to know that it's reaching all of these people online. And I get all of these messages from people saying how much just seeing it helped them. And yet in my own life, it has been challenging. Her family struggled with it. And a lot of my friends and her friends, they respect the work I'm doing, but they don't often bring it up. I think they don't really know how to talk about it.

And it is a very strange and unique position I find myself in sort of openly living through those times very publicly.

00:10:48 Caro

Yeah, I think it certainly isn't. I cannot imagine how hard that would be.

And speaking about being confronted with Paige's death over and over again, usually people, when they experience something like this, they try to find like a getaway. And most people find it in their job or they concentrate on something really hard.

And as what we see now, you are not only surrounded with Paige's death in your private life, but also on a sort of professional level, since you are writing those articles and since you're building the caregiver community. Do you think that it has sort of helped you deal so intensely on so many different ways and levels with her death? Or is it hard being confronted with it all the time and not having this sort of escape from it?

00:11:49 Mark

Yeah, that's a really insightful question. It's one I think about a lot.

There have been many times where I've thought, "Gosh, it sure would be nice to just go spend my time doing something completely unrelated to reliving these times."

There's a few factors that have made focusing on it, I think, the right choice, you know, the largest just being, I think it's important and I want to tell the story and I just feel that need to do that.

But, you know, we moved here to San Juan Island right after the COVID pandemic had shut down things in the United States. And I had all of my marketing clients I ceased working with. So we moved here to San Juan Island and I didn't have any marketing clients. I didn't have a job here yet. Paige was a teacher. That's how we found our way here. She was the

history teacher at the high school here on the island. And before I started picking up any marketing work again, she got sick. And so then for 3 1/2 years, I was her caregiver.

So by the time she passed away, my entire life had been her and her cancer and her cancer journey and caring for her for quite a few years. Before that had been the COVID lockdown. And I didn't really have much of a through line left. I didn't have a good social fabric here on the island. I didn't have a career here on the island. And so what I had was thousands of photos and videos and a whole lot of very challenging experiences. And it just felt like the right thing to do.

You know, it feels like I have this a deep well or a mine full of valuable things and hard things to share. And they seem to be of value to people. But there are definitely times where I think it would certainly be easier to go do other things. But there's a lot of little pieces, including the fact that I do still live on this tiny island and there aren't many other options. And so it sort of feels like the circumstances have aligned to sort of just make it clear to me to keep focusing on this story.

And this winter and fall especially, as the days get shorter, my plan is to really spend the next four or five months here on the island really being diligent about telling the story start to finish. So far it's been bits and pieces as I felt an attachment to them. And my hope is that by really telling it start to finish and really working through it and processing it that way this winter, the next spring, maybe it will be time to still be in this space, still be connecting people, but begin thinking about what the next chapter of my life looks like as I bring in new things and regrow.

But again, there's been many difficult balances to strike and that one you named has been one of the most challenging and it's something I think about a lot.

00:14:55 Caro

Do you now have a way to sort of get away?

I mean, you said you're on this tiny island and if you plan on focusing on the story from start to now in the winter months, do you sort of have a plan to have this sort of escape or do you plan on making a harsh break afterwards to move on?

00:15:23 Mark

It's a good question.

I think a lot of it just comes down to having a better routine, like having set kind of office hours where I'm living kind of in that time and working through it and then being really diligent about keeping the work sort of within that space. You know, that's not something I've done much up to this point. I've sort of let it be something I'm often thinking about, you know, always thinking about. So I think just building that work-life balance and, you know, as I'm going through my own grief process, there's the stages of grief. There's times you feel angry, there's times you feel numb, there's times you feel depression. And so as I go through

those different stages and feelings of grief, all of those also sort of affect whether I want to be telling the story, how I tell the story.

So I don't have specific answers to some of these questions, but everything you are asking are the questions I ask myself. And I definitely, this summer, I left the island a lot. I explored Washington state a lot more. I went on some adventures and trips and I really hadn't left the island for the last two years of Paige's life simply because I just didn't really have it in me.

You know, I could have, you know, we had the flexibility. But I was just, I really had allowed myself to get very locked into that caregiver cancer mode, which is very common from having to talk to people online. It's… There's, like, code-switching between different behaviors.

And when you're in that kind of caregiving trench, I call it, just feels very, very difficult to come up from that and go enjoy anything, much less travel, logistics, things like that.

So as I rebuild my life, getting off the island and traveling are a big priority. This winter, I'm definitely going to reconnect with old friends, go see some of them.

But it's important. You know, it's important for me to do now, and it's important for a lot of the people I speak to online. Isolation is the number one thing that people going through what I went through talk about. Isolation is the number one challenge of caregiving and illness. And most of that isolation is sort of self-imposed. It's not that travel is impossible.

It's just that it feels impossible or that it feels maybe like there's that, perhaps it like traveling and enjoying life is something one should be guilty of when someone around you is sick or dying.

And there's a lot of sort of complicated pieces to rebuild there. But for me, it's mostly a matter of just stamina and desire, just rebuilding that kind of desire to be alive and to live fully after my life being that kind of decline for so long. That switch has been difficult.

00:18:37 Simon

I would like to get back to something you said a few minutes earlier, like the reactions that you got online that showed you that there was a kind of demand for that kind of content, or maybe not demand, but a reaction where people maybe felt seen in their own situation through your experience and the story you shared that from what I gather seemed kind of evolved over the year that you did all these social media activities and build the kind of community in a way or maybe many different, many, many smaller communities.

And I think that's also like very interesting aspects about the social media time we're living in where we get to connect with so many people worldwide, maybe even who share similar experiences and who 20 years ago wouldn't have the opportunity to connect in that way. And get also reassurance in a way about their own situation.

Because what I found interesting when I prepared for our podcast today was that I didn't think too deep, I think, about the role of caregiving in some of the terms that you bring up, like, of course, like the physical aspects, the logistical aspects, also the emotional and mental aspects. But I think one quote that really stuck with me was like in one article I read was that you said as a caregiver, it was your role to live in reality.

Like others were allowed to hope, even though there was no hope. But you were not allowed to hope. You were the one who had to keep the strings together to keep everything going until the last moment. And I found that a very powerful idea and image and something that not many people think about maybe in that situation. And I would like to know: How did it feel to have that kind of role, especially when you knew others maybe in the direct vicinity could have that same role but didn't?

And what kind of connections did you make with other people in the aftermath, like who maybe said, “Hey, I had a similar situation or I am in a similar situation and you are supporting me or helping me by doing this content”?

00:21:11 Mark

Sure. Yeah, it's a good question.

You know, during the cancer years, what would happen is… Cancer is so complicated, and Paige had many tumors and anytime news came in, it would be very multifaceted news. There would be tumors that had grown, tumors that had shrank, stents that had… There's so many things would be happening. It's not a two-dimensional disease.

And over time, Paige needed hope and she had terminal cancer. There was no hope in a certain way to look at it. And so when you're fighting terminal cancer and you want to live for as long as possible, where are you going to find that hope? And so for Paige, a lot of that came from focusing on the positive news that would come in these very large, complicated pieces of feedback we'd receive from the oncologists.

And then over time, what would happen is when she felt good, she'd talk to friends. She'd talk to family. And when they asked how she was doing, she'd share some of the better pieces of news. And then when she didn't feel well, she wouldn't talk to people and she wouldn't share the negatives. And so over time, what would happen is everybody in our life and her life, they would just tend to hear the good news at the good moments, but they would not be present sitting by her side like I was for all of the low points.

And from talking to people online, that's really where the isolation of caregiving often comes from. And Paige and I talked about this constantly, you know, and I was always trying to find a solution, but there really is no solution because she needed that hope. And it didn't really benefit her or anyone else for her to be telling more people more hard news. But it does result in a situation where, as the caregiver, you're really living in the harshest realities all the time. And everyone else in your life gets to hear sort of the cherry-picked, more

positive pieces. And you don't even realize it's happening always in the moment. And I'm not sure Paige realized it was happening.

But at her funeral, I talked to somewhat close family members, like uncles, aunts. And many of them told me that they really didn't realize how sick she was right up until she passed away. And looking back, it's just one of those factors of communication where, when every communication just tends to focus a little more on the positive, you wind up feeling like you're the only one who really is living in the reality of it when you're the caregiver.

And from talking to people online, that's very common. And there's a lot of types of caregiving, a lot of people who care for someone who is ill or dying, but this kind of isolation and communication, I think, is worst when you live with the person. If you're a partner or you're living in the same home, that's when you're really subject to the full reality of it.

And I think that's when you really see how different other people's image of it is. And I think at every point in the process, every person wants to have some hope. And so I think everybody else is always putting a positive spin on it intentionally, unintentionally, and it's like a game of telephone where just a little bit of positive spin over and over again results in people having really unrealistic pictures.

But someone has to be fully aware of the reality in making the medical decisions. You can't be making decisions medically about treatment or end-of-life care based on sort of a rosy, overly positive outlook. And so the caregiver is often the one or the partner, whoever is sort of closest to it, other than the patient, I think often winds up in a position where they're the one who is sort of forced to be always aware of the hardest truths and often is the only person who's aware.

So it's a very complicated thing. It's one I had not seen many people talk about and it's something that people reach out to me a lot. I think that's one where a lot of people feel it and they don't really know how to put into words or they don't know how to communicate it. And so that is one that a lot of people have reached out to connect over, just to share how closely they identify with that feeling.

Yeah, it's a hard one. Did it ever feel kind of unfair to you that you were the one who had to live in reality and you were basically the only one who didn't have hope? So it did. That's the complicated thing about all of this is I would sit down and I would… Yes, it all felt unfair. It all felt horrible. It all made me angry. And yet, what was there that I could or should do differently?

You know, that's kind of the catch-22. The challenge of so much of this is if it had… You know, there was no… There was no better path. Me calling all of her friends and family and telling them that she was sicker, it wasn't really my decision. It wouldn't have helped her. It wouldn't have helped them.

I think one of the hardest parts of this entire experience is all of these things we're discussing that were problems didn't really have solutions. They're just challenges and

there isn't always a… I don't really know what I would have done differently to solve these things.

I think, in my opinion, being open and honest with everybody in your life in a caregiving situation or cancer situation, it makes it better. It allows people to know how serious things are. It allows people to know how much help you need. It allows you to just feel better having gotten things off your chest. But I'm a little unique in that. I'm also sharing grief publicly on the internet. And a lot of people don't do that. They don't share it at all.

So my sort of desire for sharing truth, I understand, is not always what others are comfortable with. And so I think one of the things that made it so difficult is I was aware of these problems and these challenges that I'm telling you about now, but I was also aware that there wasn't really a solution in the time.

And Paige did need that hope. And it would… I genuinely believe that she probably lived longer and fought harder because she was able to maintain that hope. And a big part of maintaining that hope was helping other people hope. And what could I have done to really change these problems other than take that hope away to make myself feel a little less isolated? And that's not a trade I would have willingly made.

00:28:36 Jörg

I would definitely love to come back actually to why you actually choose to put it on the internet. And I think this is an important reason why we are talking today.

But let me first pose another question. I'm reading for, I think, now two years, a book by a palliative nurse or end-of-life caregiver she is. She's American. And it's very impressive. So I can only take one chapter at a time and then I have to stop because end-of-life care is very special.

Did you have any help? I mean, did you inform yourself by internet or did you have some nurse or caregiver actually that who supported you?

00:29:23 Mark

We did. So, Paige's team of doctors were wonderful. Also, because we were on this small island, we could literally just walk down the hill. Our little hospital is right at the base of the hill here. And we would go to the mainland for a lot of care. But because we were on this island, very small community, everybody knew what was happening. So socially, we had a close community. We had access to her team at the base of the hill.

But it is a common problem that people talk to me about is they don't realize how much help they need until it's too late. And looking back, I absolutely wish, I absolutely would have benefited from having professional caregivers or in-home care earlier in the process.

But it's one of the situations where it's just so much is happening so fast that by the time it sinks in and you realize how bad things have gotten, it's gotten worse again. And you're just sort of constantly being swept along.

And so Paige didn't end up going on palate end-of-life in-home hospice care until about 10 days before she died. You know, she was still walking and it was just me and her. So it was just Paige and I till really the final weeks of her life. And then about two weeks before she passed away, she had a really bad fall.

I rushed her to the… And she went to an intensive care unit on the mainland. That had happened before, that exact same problem, exact same cycle. And that was when they were recommended that we set up a home hospice. And I called hospice. I set it all up. And that was when all of a sudden we had a nurse, caregivers, all of that.

And then eight days later, Paige passed away. So really until that final two-week period, we did not have in-home care. I really didn't have that team. And on the one hand, it would have been amazing to have that help. But the reality is 99% of this cancer battle was just sitting on the sofa with Paige watching TV. On a day-to-day basis, it really is just kind of… You're just kind of waiting. It's about stamina, maintaining hope, maintaining positivity. There really isn't much to do on a day-to-day basis.

We talk about cancer battles and wars, but you're really just waiting while these battles play out inside a body where you can't really see them. You're only getting updates every month or two from scans. And I would have loved to have a whole team of people coming into the house just for the social and emotional support, but I don't know what they really would have done right up till the end.

But the caregivers I met in those last few weeks were just unbelievably amazing. The people who do that work, who show up for the absolute hardest part of what I went through with Paige and then do it again and again and again, always losing patients. The people that I've met who do that work are just amazing human beings, every single one. I have so much respect for them and I've gotten to know a few since then, which I'm very thankful for.

00:32:50 Jörg

It's incredible, this kind of jobs, definitely. But you also teach people what you are doing or am I misunderstood here?

00:32:59 Mark

I'm not a teacher myself, but my mother, father, brother, sister and Paige are all teachers. So I would say that I am a teacher by osmosis in a way. I've sort of absorbed the teaching lifestyle and it's probably in my blood at this point as well.

So I've truly been around teachers my entire life. And Paige was an amazing teacher. And my background was in marketing and copywriting. So I pursued screenwriting for a time in Los Angeles. Yeah, so those pieces all really fit together. The educational component and the

teachers, I think, definitely contributed to my ability to share knowledge and educate, but the writing background and the interest in filmmaking sort of provided a lot of the pieces as well.

So it definitely felt like I, just by nature of the people I've been around in my family and my life, wound up with the proper set of skills to tell this story in the way that I'm doing it.

00:34:06 Jörg

Yeah. And at the same time, we all know that social media can be a blessing, but also a curse somehow. Did you receive some hate reactions or critique where you said, “Okay, this is far beyond what actually I'm going to accept,” and what it do to you?

00:34:26 Mark

It’s honestly far, far, far less than I would have expected.

You know, I would have expected a lot more. I definitely do get… People will leave comments that are angry or hateful or people will leave comments that these are things that shouldn't be shared. But by the time I find them, there's often 15 people who've responded to them on my behalf, sort of arguing for all the reasons that it's helped them. So surprisingly, all of the things that you might expect would have been horrible and toxic about what I'm doing really have not happened that much.

The support and the feedback has been overwhelmingly positive. And a lot of the time when people reach out with something negative, it's just very clear that they are suffering or struggling. And I'll often respond to them, which they do not expect. And I'll respond to them just sort of openly and honestly. And half the time they immediately apologize or they actually just sort of realize maybe they shouldn't have left that. And the people who double down, they're clearly going through something very difficult.

So I've actually been very surprised by the overall positivity. And I've actually been very surprised that the social media algorithms, I think, actually really want this type of content. Like, yes, social media, if you just want pure numbers, you kind of hack the algorithm with a bunch of nonsense. But I think the platforms are aware that they're getting flooded with AI and garbage and I think a lot of the platforms and the algorithms are… They really want people to be telling stories and they really want people to be doing more serious stuff.

And I think that that's one reason that this story has been able to reach people is there really aren't that many people who are trying to do… Tell serious stories on social media. And you're not going to get 55 million followers telling tales of grief, but there is a lot of room to connect with a lot of people on serious topics. And now that I'm doing it myself, I, of course, have connected with other people doing it. And I've actually been pretty impressed with this side of social media.

It's definitely given me back at least a little bit of hope that there are some positives to social media out there.

00:37:00 Jörg

And talking about how… What would have been a precious reaction you might share with us?

00:37:07 Mark

You mean like a negative one or a positive?

00:37:10 Jörg

Yeah, a positive one. Yeah.

00:37:11 Mark

Oh, just… I mean, it's so many to count.

That's actually one of the hardest things as well as I will get so many thousands of comments and I genuinely can't respond to them all. But the… The most powerful and precious ones are when people will reach out to me directly and I'll open the message and it's just already… It's clearly off the screen already, just an incredibly long message. And it'll just be someone sharing their entire story and telling me that they haven't really felt comfortable sharing that with anyone.

And so there's… As I… I'm someone who clearly knows that there's a power to just getting it out there and just sharing the story. There's this unburdening feeling, which I think is very important and very powerful. And my videos and my channels for hundreds of people have been an opportunity for them to just share that with me, and they don't really expect a response most of the time. And they're… I try to respond to all of them and they're often surprised.

But just the fact that people are willing to share the story, but more so just knowing that they had that opportunity to get it all out and knowing personally how powerful that is has been very humbling and meaningful. And that's what led me to think of starting this community as I realized really people, I've gone through one cancer battle. I cared for one person. I'm not an expert on cancer. I'm not an expert on caregiving, but where can I add value? And I think it's connection and communication.

And so from getting all of these messages from people, that's when I started realizing, like, it's just… People really don't feel like they can share it with anyone. And I get it. It's like…

The thing about a cancer battle is it affects every part of your life. And it's hard to make small talk. It's hard to… It affects work and everything. So it suddenly feels like every conversation you're having with everybody is about cancer. And when other people don't know what that's like, it's hard.

So yeah, the messages I get from people where they share their whole story and I can tell that it's really their first time sharing it, those are the ones that always hit me the hardest because I can tell how much it's needed and I know how much it was needed for me.

00:39:45 Caro

Yeah.

And maybe connecting to what you just said, connecting people and giving them also a space to share their stories. You have just launched your project, the Caregiver Community, in October. Would you like to tell us a little bit about this?

00:40:06 Mark

Yeah, so it's still in what I would call kind of like an early beta phase right now. And so I've just been inviting people to help me build it and test it. And the goal is to create a community where people can just share these things openly and honestly.

The challenge is knowing how to do that, because it takes, I mean, as I've talked about, a lot of people don't feel comfortable sharing these things and talking about them means thinking about them, facing them. So the challenge that I am facing as I build this is: Do I just create a blank slate and allow people to come and share their stories? Or do people need more than that? Do they need some coaxing? Do they need some prompting? What's the most useful way to help people who are going through what I went through share, feel comfortable sharing, want to share? And how do you keep that conversation going?

So that is something that I'm working on actively right now. And in looking up sort of best practices for communities like this, there's not a lot of comparable situations. I've run online communities. I'm a member of a lot of online communities, but this is a rare situation where the topics are very hard and people will be dying. That's the other thing is there's caregiving and then there's also grief.

So there will be people in this community who are before the death. There will be people who are after the death, and perhaps those people want to talk to one another. Perhaps they don't. So the goal is to build a community that allows people at every stage of a caregiving journey and a cancer journey and a grief journey to just feel comfortable sharing. The challenge is building a framework that helps people do that.

So that's my goal right now. And there's about 400 or 500 people in there right now.

People are welcome to join for free if they wish to at this point and just come help and share. And I've been getting good feedback as I continue building it. And once it gets to a point where I feel like I found the right mix of conversation topics, just like the right amount of structure to really help people share comfortably, I think that I'll consider it kind of officially launched.

And I have some good support from various people and organizations, including Mighty Networks themselves, the platform that I hosted on, they're actually supporting it and they've given me a lot of support in building it because they want to foster communities like this as well.

So yeah, it feels, for this whole year, I've sort of wanted to figure out what I could offer people that felt useful, but also where I wasn't outside my lane, so to speak. I can't offer advice on cancer or medical advice. And so this feels like the best thing I can offer. It's just a challenge figuring out exactly how to build it. But that's the work right now.

00:43:27 Caro

Yes, and we would love to share the link to the caregiver community.

And I must say I browsed through it and I just had a cancer diagnosis in my family, in my close family this summer as well, which was the first time for me connecting to this topic on a closer level or having to deal with cancer as a diagnosis in a family.

And I saw the questions that you posted that everybody is afraid to ask or might not know how to ask. And I must say they have really helped me because I was afraid to actually ask these questions.

But as you said earlier, you are planning to concentrate on yours and Paige's story this winter. Do you have any plans for the future regarding this, maybe a book or also plans for the caregiver community?

00:44:30 Mark

That's my hope. I think my hope is to definitely write a book about the process. Originally, my thinking was, “Oh, it'll be a non-fiction sort of self-help book.” But then I've realized, really, I think it's what I have to offer is the narrative, at least from a storytelling standpoint. It's just sort of representation is important in so many ways in so many communities and just seeing all of this shown.

There's also not a lot of men talking about these topics online, at least not in America. You know, most of my followers are women. I'm taking an online sacred death care course. I'm one of two men in 180 students that have gone through this course. So I do, I think there's also that element as well where, you know, there's a mix. There's just a lot of groups overlapping here that don't always feel comfortable communicating about these topics.

And I think just purely the storytelling and putting it out there is the direction where I can offer the most value writing-wise. And so I've been… The plan is to really tell the story start to finish on Substack. I think Substack Essays, that's been a really good platform that I just recently joined. It's really built for this sort of longer-form writing. And over time, as I begin telling that story in larger pieces on Substack, I think working toward a book is my goal on the storytelling side. And then in the sort of community and connection side, that's where the caregiver company, caregiver community will come into play.

There's a lot of moving… How all of those pieces fit together is a good question. It's one I think about a lot, but I think those are the sort of two unique pieces of value that I can bring to people from this experience. So the plan is definitely to work toward a book. And I think this winter will be the time that I go in that direction.

00:46:42 Simon

I would like to ask one last question.

Looking forward to the community you're building and the content you just talked about. And also getting back to what you said about the feedback you receive on your social media. Would you say that this whole area of dying, death and grief is something in the social media age we're living in that is still somewhat protected from the more vile elements that show themselves online and that someone who joins or interacts with such a community constrains himself and then feels like the seriousness of what's happening and what we are talking about here because it's such a basic human experience that everybody can relate to on some level and that people somewhat instinctively feel, “This is no place for me to share, I don't know, stupid jokes or the hatred I'm feeling about something else or a meme that doesn't make sense in that situation”?

That is a topic that is kind of keeping these things from happening because deep down, people realize, even if I'm not affected, this is something that doesn't call for unwanted action in some way.

00:47:55 Mark

Definitely.

I think, as you'd hope, the number of comments I get that are trolls or things like that are, I would assume, far below the kind of average online. And when they do happen, there's been situations where somebody will make a joke or a comment that I actually find humorous and kind of appropriate, because once you've… It's one of those situations where, like, Paige and I would make jokes about cancer when you're battling it, like when you're actually in there, you have to sometimes have humor about it.

And so there are always times where people on the outside are actually more hesitant to make any humor of it. So there are times where people will leave jokes or comments that I actually think are perfectly fine and maybe even healthy, especially if they're going through it. And other people will respond to them negatively. And I'll actually jump in and be like, “No, it's okay. Like, you know, they can make… They can make that joke.” You do eventually, you do have to find some humor in these things sometimes. But it is a very fine line. And thankfully, that line is not crossed by very many people.

Yeah, I think, you know, it's serious enough content. I think, you know, the algorithm is showing it to people who tend to be older, more mature. And so, you know, just by all of the

many overlapping variables and factors, I thankfully have been pretty immune to the sort of nonsense, offensive comments one finds on the internet.

Then again, I usually don't dig too deep. I'm sure if I scrolled all the way to the bottom of some of my larger posts, I'm sure there's some pretty strange ones buried down in there, but you know, they don't make it to the top. So thankfully, I don't always see them.

00:49:50 Jörg

Mark, thank you so much for joining us and sharing your experiences and your thoughts with us. And we are really looking forward to your next projects and what we can learn from you again.

And yeah, thanks again for being with us. Have a nice day.

00:50:09 Mark

Yeah, thank you so much for having me.

I really appreciate your questions. They were particularly insightful.

It's been a lovely conversation and getting to meet you all.

00:50:19 Caro

Thank you.

00:50:23 Simon

Thank you.