

SEEKING THE EXTRAORDINARY

Ep 12 - Adam Hayden: Living While Dying

JUNE 16 2021

[00:00:00] Seeking the Extraordinary is sponsored by The Colony Group, a national wealth and business management company that seeks the extraordinary by pursuing an unrelenting mission of providing clients with peace of mind and empowering their visions of tomorrow. To learn more about how The Colony Group manages beyond money, visit thecolonygroup.com.

Michael Nathanson: Welcome fellow seekers of the extraordinary, welcome to our shared quest. A quest, not for a thing, but for an ideal. A quest, not for a place, but into the inner unexplored regions of ourselves. A quest to understand how we can achieve our fullest potential by learning from others who have done or are doing exactly that.

May we always have the courage and wisdom to learn from those who have something to teach. Join me now in Seeking the [00:01:00] Extraordinary. I'm Michael Nathanson, your chief seeker of the extraordinary.

Ladies and gentlemen. Get ready for a human jolt of concentrated, pure inspiration. Get ready to learn. Get ready to be emotional. Get ready to smile and get ready to cry. Today's guest is a philosopher, writer, advocate and community organizer. He's married and has three young children. He's witty, charming, brilliant, and full of life.

And in 2016, he was diagnosed with glioblastoma, one of the deadliest and most common forms of brain cancer. Glioblastoma or GBM has a median survival time of [00:02:00] approximately 10 to 16 months and a five-year survival rate of only about 5%, making our guest's survival for five years, quite rare. GBM is the form of brain cancer that took Ted Kennedy, John McCain, Beau Biden, Tug McGraw, Ethel Mermen, and Neil Peart from us to name only a few.

As our guest says, though, he is living while dying. He is published on medical education, cancer survivorship, and the philosophy of illness in both the popular and academic press. He completed the requirements for his graduate degree in philosophy while in active cancer treatment and was recently awarded the distinguished alumni award by his university.

He's an investigator with the patient centered Outcomes Research Institute, grant funded brain cancer, quality of life collaborative. He's an American Association for Cancer Research scientist survivor program [00:03:00] participant. A Stanford university medicine, ex E patient scholar and speaker, and was a speaker at the 2019 End Well symposium and event focused on de-medicalizing the end of life. As a champion for early intervention of the palliative care service, he offers a unique perspective on the end of life as a young dad and husband. He served three years as a reviewer for the peer reviewed cancer research program, a grant funding organization that resides within the Department of Defense.

And he now serves this program on the programmatic review committee. He also served as an advisor on two projects with the broad Institute at MIT and Harvard. He is a regular lecturer in hospital settings, and he's delivered, invited talks at the Fairbank Center for Medical Ethics, the Indiana University School of Medicine Center for Bioethics, the St. Louis [00:04:00] University Center for Bioethics and the Indiana University School of Medicine, palliative care fellowship program. Please welcome the extraordinary Adam Hayden. Welcome Adam.

Adam Hayden: Well, thank you so much, Michael. What a generous introduction. I'm honored and I know folks can't see me right now, but I am blushing under my beard.

Michael Nathanson: Well, that's an intro that I think only tells part of the story of you, which is even more extraordinary. And I have to say that I had some reluctance, writing out what I wanted to say about you in your introduction. I follow you regularly on social media and in a little while, I'll give you an opportunity to tell people how they can follow you as well but, I'm pretty sure that you have indicated directly if not indirectly, that you don't want to necessarily be defined by your brain tumor. And yet the reality is, is that we are together here today. [00:05:00] Frankly, because of that. Am I right to, to think this way?

Adam Hayden: You are right about that. And it's interesting.

It's one of those things that, you know, the thing that makes me interesting to folks, uh, is also a thing that, you know, puts my life at risk. So it's a strange space in which to traffic, for sure. I did resist this idea in fact, I said early on, I said, well, I'm not going to be a cancer mascot. That was a declaration I had made early on, shortly after my diagnosis. But in fact, oh about a year or so later after I made that sort of proclamation on my personal blog, I said, you know what, I'm going to embrace this. I will be a cancer mascot because I was finding that there was tremendous value in that space for myself and for others.

Michael Nathanson: Yeah yeah. And boy, I have to tell you, I certainly agree with that. Let's, let's spend just a few minutes talking about your life prior to your diagnosis, just so we can learn a little bit more about you.

Adam Hayden: Yeah, [00:06:00] absolutely so there are layers of, I mean, like all of us, you know, I think our identities tell us important things about where we end up in the world and also the identities of those who are around us. And there was something about these big questions that are presented through illness that were kind of in my life from the start. And I'll tell you what I mean by that. So my dad is clergy, my dad's a pastor. So I grew up knowing that the work of my dad was to visit folks in the hospital to preside over lifecycle events.

And so there was something about asking big questions and understanding kind of the fragility of life that was, there from the start, and in fact, my sister, little sister, I'm the oldest of three, my sister is four years younger than I am. She was born with pretty profound, developmental and physical disabilities, and I ended up, uh, my wife, Whitney she is a seasoned veteran in the healthcare space. I, myself, right before diagnosis, I was working as a project manager, in fact, on a big [00:07:00] state-wide, Medicaid management information system implementation. There's a lot of those kind of gold star words. But so prior to diagnosis, it just so happens that there were all of these intersecting points about healthcare, about asking big questions about living closely with a sibling with disabilities. So I say Mike, that I am well-suited for illness as a result of those things. So that was what life was like just before my diagnosis.

Michael Nathanson: And you've got children.

Adam Hayden: We do. Yep. So three boys, as of, as we're discussing this today, they are nine, seven and five years old. Our youngest though was only eight months old when I was diagnosed. So, you know, that wondering how to navigate this whole world with kids and serious illness has been a big part of, me and my wife's journey.

Michael Nathanson: And you were pursuing, were you pursuing higher education? Post-college in the area of philosophy is as well?

Adam Hayden: That's exactly right. Yeah. So I did my undergrad and a terminal Master's degree [00:08:00] in philosophy and had plans to apply for doctoral programs, you know, with a young family and the way the state of higher education, often-times to get into a PhD program that requires that you move.

You know, and especially in a field like philosophy, it's pretty competitive.

You know, I mean, in many programs we'll have, applicants in the hundreds, but may only have space, you know, in the single digits. So because of that, you applied to as many programs as possible, and then you move to where you get accepted with funding. So because of that reality, and because we were growing our family, the plan was like, well, let's wrap up your terminal Masters and then we'll, you know, you can work for a few years and then we'll apply for a doctoral program. But cancer interrupted those plans.

Michael Nathanson: Yeah, yeah so let's talk about that interruption now. And, I know that you are a regular speaker on the topic. So forgive me if you've talked about this experience in the past, but I think it would be helpful for our audience to hear, how did you find out you had GBM? What was the experience?

Adam Hayden: Yeah, in fact, it, it started, I have kind of a long circuitous path, to the point of diagnosis. And so I've always been a pretty healthy guy. And I've not been very athletically inclined in my life but I've never had any major health problems, always just kind of been healthy.

And, this thing started in late 2014 in fact, the day after Christmas. That's kind of the landmark and time for us. We were unloading, an overnight bag after being with my wife's parents, the night of the 25th. And so this was the 26th and I had an experience that I'd never had before, I got really dizzy and weak, and the room was spinning around me and I didn't lose consciousness, but certainly it felt like my body was just kind of shutting down.

So I was on the floor and this was about a eight to 10 minute episode. And then I just sort of regained, recovered from that episode and everything seemed fine. So I didn't worry about it you know, as, as oftentimes we do kind of brush these things under the [00:10:00] rug and I just thought, oh, well, I'm stressed out.

And you know, it's the holidays. And I was a grad student and working at the time. So it was easy to dismiss that until it happened again, about three months later in March of 2015. And that began this journey of wondering what's happening. Maybe it's a vertigo, maybe some sort of circulatory issue is some sort of nerve damage.

So it was about a year and a half of seeing specialists of trying different things until these episodes were increasing in frequency and duration and intensity all the way into the spring of 2016. When finally my doctor was like, we need to get you to an MRI. And that revealed this primary brain tumor, a pretty sizeable mass that set everything in motion then to get the diagnosis and surgery, et cetera.

Michael Nathanson: So you were living with the tumor for about a year and a half you believe before diagnosis, which is extremely rare. Is that not?

Adam Hayden: Yeah. So as the neurosurgeon, really unpacked this for the first time for my wife and I, he looked at the scans and in fact called us back to his office.

I mean, we were in exam room and [00:11:00] mice and neurosurgeon said this really memorable line. He said, I can't believe the person I'm talking to right now is the same person whose scans I was just looking at in my office. So it was a really big, it was a seven centimeter mass. And my neurosurgeon's read of this is that it was a slow going, it's a rather slow growing non-malignant tumor for some time that then underwent a malignant transformation. So it became more aggressive and that increase in symptoms came with that more aggressive turn of the disease. So it was a slow growing tumor for, yeah for who knows how long. I mean every bit a year and a half, if not a little longer.

Michael Nathanson: Yeah, I think I read in one of your writings, you described seven centimeters as about the diameter of a baseball. I didn't actually go and measure to see if that was accurate, but just to give our listeners some perspective, we're talking a big tumor. Could you, I'm assuming you've learned so much about your disease. You're a very learned person. Could you give us [00:12:00] some education on glioblastoma?

Adam Hayden: Absolutely. Yeah. So, you'll hear some folks use brain tumor and brain cancer sometimes interchangeably, you know, when we're being thoughtful, we like to use the separate terms, because not all tumors are necessarily malignant. And, uh, that doesn't mean that it's a good tumor and we say there's no such thing as a good brain tumor, even a non-malignant or some folks will say benign tumor, if it grows large enough, these can be lethal but glioblastoma is one of the malignancies and in fact, the highest grade malignancy. And now when we say highest grade, that's different from staging. So some folks are used to hearing, you know, stage three, stage four, this and that, within the brain tumor space, those tumors are graded as opposed to staged. There are 120 or so types of brain tumors in all, and glioblastoma, comes from a mutation of these cells in our brains that are called [00:13:00] astrocytes.

Astrocytes look like little stars. And you hear other such as astrocytoma, uh, is another name for glioblastoma. So this is a primary brain tumor. You heard me say that the difference between a primary brain tumor and a secondary brain tumor, is that a primary brain tumor arises within the brain where a secondary brain tumor would be like a brain metastasis, for example, from another cancer site in the body. So primary brain tumors, they start in the brain and they tend to end up or stay in the brain. Whereas other cancers can spread throughout the body and to the brain, primary brain tumors, stay right there in the brain so far as we know.

Michael Nathanson: And thank you for your comments about brain tumor versus brain cancer. I think that's a very important message. And Adam as you know, I have a brain tumor, I don't have brain cancer, but I prefer when I don't use the term benign because I agree with what you said. It's very rare to have a [00:14:00] benign brain tumor. In my case, it's something that could take my vision from me.

And, there's only a small chance of it taking my life, but I don't think of it as benign. I appreciate that message. So what kind of treatments are available for GBM?

Adam Hayden: Yeah. So glioblastoma unfortunately has a pretty small menu of treatment options. It's a really treatment resistant disease and, that gets into a science that likely would bore the listeners.

And certainly, I'd be speaking out of my league pretty quickly, but the treatment options that are available, the standard of care therapy that we've had since about the mid-nineties, includes surgery, and so if you can have a near complete resection in the clinical jargon, this is a gross total resection, but as much of the tumor, as you can remove through surgery, the better. And then we do have a radiation therapy. Typically this is a daily radiation therapy for a six week course, along [00:15:00] with that will be a chemotherapy, that currently the first-line chemotherapy is one called Temozolomide, this is an oral chemotherapy, it's a pill that you swallow now it doesn't mean that it's any less toxic to the body, it being a pill that you swallow but you can take that at home whereas, folks with other types of cancer are used to going to infusion suites at outpatient facilities or at the hospital where their chemotherapy is administered by I.V.

So the chemo for glioblastoma is an oral pill. That starts with a daily regimen. And then there's a maintenance phase where you have five days each month of high dose chemotherapy, and then 23 days off, to let the body sorta recover. And then you repeat that cycle again. The standard of care protocol would call for six months of that cycle.

When you speak with patients, oftentimes, there's various links that I had 11 months of that cycle. I know folks who have had even longer than that.

And [00:16:00] certainly there are many patients who have had only the six-month cycle or even less, if their body began to, you know, not tolerate that chemo as well, but those are the typical, you know, surgery, radiation, and chemotherapy. Uh, there are some experimental treatments. So I'm sure a lot of folks have heard about immunotherapies. Immunotherapies have been very successful in many cancer types. We just have not seen the traction within brain tumors or brain cancers for effective immunotherapies. That still is a really promising area of research. And we are seeing some incremental improvement there. We're learning more about the brain, but the immune system of the brain is a little bit different from the immune system of the body. So that presents some challenges when administering immunotherapies. There, you know, I mean there's stereotactic radiosurgery, which is a really, some people call that gamma knife.

It's a you know, high energy radiation, but very targeted. So some folks, will have that stereotactic radiosurgery. There's also tumor [00:17:00] treating fields, so this is kind of a newer therapy. Maybe one of the, the more recently approved therapies, this in fact is a cap that you wear on your head that emits an alternating electric field, through your brain. That sounds pretty high tech but as cells divide, uh, there's a certain process that relies on magnetism in our cells, to actually divide and this alternating electric current interrupts that process. So it slows cellular division, and that tumor treating fields, that's rapidly becoming a standard of care therapy.

Michael Nathanson: But that's really the only relatively newer therapy. The other ones have just been around for a long time.

Adam Hayden: You're exactly right. Yeah. I mean, I think four approved treatments in all in three or four decades.

Michael Nathanson: Yeah that's a shame. So just talking about your experience, I think you just said that you did Temozolomide for 11 months. Did you have surgery and radiation [00:18:00] as well?

Adam Hayden: That's right. Yeah. So, my surgery, in fact, was performed while I was awake. So that's, you know, I wouldn't say that that's common, but it isn't as rare as folks may think to have this awake brain surgery. Because the brain controls so much in the body, that when you can perform a surgery while a patient's awake, you can mitigate the risk to sort of those eloquent functions that our brain is responsible for. So the placement of my tumor, you know, in fact, and we may discuss this a little bit more in depth if you want to but I, had a risk of permanent left sided paralysis based on the location of my tumor. So my surgeon decided and decided with colleagues in a meeting called a tumor board, given all the jargon, I suppose. But that group of surgeons and oncologists decided that by performing that surgery while I was awake, we could limit that risk, to permanent paralysis for me.

Michael Nathanson: Yeah, I actually, I read in one of your writings, or actually you mentioned this during [00:19:00] your N Well speech and I thought it was just, it made me feel emotional to read this because I imagined how someone would feel with this kind of question and just the emotion, the terror, the fear. And I'm curious about your experience because I'm only speculating on what was going through your head. But you write that your surgeon asked; Adam, I have removed the majority of your brain tumor. I can continue to resect more tumor to be more aggressive, but this comes at the risk of permanent left sided paralysis, or we can stop the procedure now. Protecting most of your motor function, but leaving a residual tumor in the margins of your surgical cavity, Adam, what do you want to do? I mean, that's just, it's unimaginable to have that conversation with someone who is performing surgery on your brain. So what did you decide?

Adam Hayden: Yeah, my, my knee jerk reaction to that [00:20:00] was to say, well, you know, listen, I don't want to be back here in this operating room in a year because I made the wrong decision today. I mean, I think I was leaning towards let's be as aggressive as possible. I said that thing about not wanting to make a mistake, not wanting to be back in a year.

And I think there's an interesting dimension here that intersects with my kind of philosophical outlook, that's about what did the surgeon really know at the time?

And was it more than the surgeon was letting on and is that good or bad? That's a kind of a medical ethics question that we can set aside, but I was thinking about, you know, let's be aggressive you're if you're in there might as well scoop out as much as you can. But my surgeon said, you know, you really have to make a decision based on where your quality of life is today. Not what you think could be the case in the future. Such sage advice. And so immediately I thought of our three boys, I had mentioned our youngest was only eight months old and I thought, boy, permanent left sided paralysis.

If we can avoid it, that certainly doesn't [00:21:00] seem compatible with being a young dad to young kids. I mean, I, I don't know if I mentioned this. I was only 34 so, you know, really just kind of starting this whole dad, parenting thing. And so I said, well, let's end the procedure now then let's protect as much of that function as we can. And then let's just sort of, I mean, you're rolling the dice on biomedicine at that point, to manage whatever remaining tumor may be in the surgical cavity.

Michael Nathanson: So what are your limitations now? Do you have physical limitations now? Because of the surgery, because of the tumor, because of both?

Adam Hayden: Yeah, the brain certainly is the easiest organ to damage and the most difficult to heal. And I think that's been just, everybody's kind of collective consciousness around traumatic brain injury and considering sports, et cetera. I did have significant impairment after surgery. So I was, I mean, to the point where I did have a lot of paralysis on the left side of my body, this was due to a lot of swelling and some fluid collection in the brain. It was [00:22:00] concerning to lay in bed and to not be able to use the left side of my body. I mean, I was reaching across myself with my functional right arm to sorta move my left arm around. I had very little movement through my left leg. When my surgeon visited me the first time after surgery you know, I expressed these concerns and he asked me to wiggle my toes and I could just a little tiny bit. And he said, you know, if you can move those toes, that means we can get it better. And so when I was medically stable, uh, we discharged me from the hospital where I had surgery. And immediately I was admitted to an inpatient rehabilitation facility where I could do intensive occupational therapy and physical therapy.

And that was a, you know, really a crazy experience. That was very, I was very independent in my life, and this was on a locked brain trauma unit. So I couldn't leave the place. I was in a wheelchair with a wheelchair alarm, so I couldn't get out of my wheelchair when I was transferred to bed, the bed was alarmed, you know, I was a fall [00:23:00] risk.

So it was in my own best interest, I suppose but I went from a very independent, you know, somebody who's been generally healthy and all of a sudden in a locked floor around other folks with significant cognitive impairment with very limited mobility and really under watch for most of that time. But thankfully through intensive physical therapy and then outpatient as well, today I still need a cane to get around. I still have seizures, that we've not been able to fully control through medication, headaches and pretty pronounced, fatigue. So I can, you know, give it my all to something, for two, three, four hours. But just that recovery time, just really drains me, you know, it takes a long time to recover. So one active day sometimes requires like two days of recovery. So that's a consideration whether it's family activities or with work, et cetera. So those are kind of the ongoing impairments today.

Michael Nathanson: Do the seizures prevent you from driving?

Adam Hayden: They do. Yeah. So I've not had my driver's license since surgery. So for five years.

Michael Nathanson: So I think that there's just so many extraordinary things about you, Adam. [00:24:00] And I'm guessing that my audience has already concluded that you are an incredibly articulate speaker and thinker. But, I think that it's not just your experience. It's your mind. It's your philosophical approach to life.

And I want to spend some time now talking about that and, my first question in that regard is a very basic question. May have a big answer. Maybe it's a short answer. Do you feel bad for yourself?

Adam Hayden: Hmm. You know, I'll say, you know, I kind of teased out a little bit, this well-suited for illness idea. I mean, this idea that my dad was engaged in and, you know, work around supporting communities through illness and stuff. So I think when I hear that question, my immediate response is that I've never had a "why me" moment that just isn't something, you know, whether that's self-pity or even just this kind of existential dread. I mean, certainly there have been, low times and I see, I mean, I'm, I am pro mental health. I mean, I see a [00:25:00] therapist, I'm not ashamed at all about that and happy to speak to that experience, et cetera.

Do I feel bad for myself? I mean, certainly there is, it's tough, you know, I mean, it's tough to the, all those plans, to go and get a PhD. And I, I really wanted to be a professor at the collegiate level, and that just seems far out of reach. And so that's difficult to reconcile those plans I had for the future, with the reality of where I am today.

Michael Nathanson: You know, so you're an advocate and that's in your bio and you are clearly an advocate and as someone who follows you regularly, I can see you advocate for many things. And in the area of patient care, you, along with some of our other mutual friends, seem very much focused on ensuring that clinicians see us as more than just our illness.

And you once said, and you just so full of great quotes. You once said that "taking the patient as only their disease, not as a person, that's a detriment to clinical [00:26:00] care. But it also harms the clinician. Medical practitioners were taught some medicine to do the good work of healing and that may not include curing." So what does all that mean?

Adam Hayden: Yeah. So I, you know, I mean, I do think, and this is, and I'll try to mention some folks just because, um, and this may be higher education, right. Is you don't, you tend not decide without attribution or something like that. So Victor Montori is somebody who kind of turned me on to this idea. You know, talking about the solidarity that's needed within healthcare. I don't think it's controversial to say that our healthcare system is pretty broken. We are a very wealthy nation here and yet it is a difficult for folks to access care. We have a terrific medical education system. And yet you look at residents and they're working, I mean, now they're restricted to 80 hours a week or so but it's just a difficult system and clinicians, even the very young ones are becoming burned out, pretty early. And so I think that it's not, a matter of a [00:27:00] patient versus a physician, oftentimes in the past, that's been the power dynamic, that it's the clinician on high and the passive patient.

And now that dynamic continues to exist. So I don't want to pretend that that's solved. I think paternalism in medicine itself is an interesting topic. But in fact, I think that it's not patient versus physician, if patient and physician joined against this big healthcare system. And so when we don't allow the time or space for physicians to get to know their patients, to spend time in a clinical encounter, that's going to contribute to burnout because just as much as I want to be seen and heard and respected as a patient, I know that that's what the physicians also want to do.

They want to get to know their patients. They want to have this sense of, they are supporting in their healing, through the encounter. Yeah so I think the more that we can storytell and get to know each other on a personal level, it's going to reduce clinician burnout and improve [00:28:00] care.

Michael Nathanson: Yeah, you quoted William Osler who I guess is a medical educator who said that "it is the good physician to treat the disease, but it is the great physician to treat the patient with the disease."

Adam Hayden: That's right.

Michael Nathanson: That sums up that thinking.

Adam Hayden: Yes, absolutely. And even before, you know, I mean, this is a long tradition. Sometimes we think, oh, well that feels, you know, new age or something like that, but even Hippocrates, you know, or at least there's this big body of Hippocratic writings.

And we think Hippocrates wrote some of that, but probably had some, some friends, colleagues and peers who also contributed to that work.

But, you know, Hippocrates said it's more important to know, what person a disease has, than what disease a person has. So those ideas have been with us. At least in Western medicine, for thousands of years, we just have to make good on it.

Michael Nathanson: Yeah you can think about the rest of the world going in the direction of big data and thinking about everything being statistics and everything being quantifiable and measurable.

And I [00:29:00] definitely get the sense that in the area of medicine that there may be a little bit too much of that. One thing you said that I really loved was you said where my case and cases like mine ultimately lead, radiographic data, immunohistochemistry and I never even heard the word before, next generation sequencing, cell-free DNA, organoids, mathematical algorithms, computerized models. We can learn so much without ever having to touch a patient. We can learn so much about the patient without every getting to know the person.

Adam Hayden: Yeah. Those, gosh, we can order imaging scans and we can take blood and do lab values. And, you know, we can construct a pretty comprehensive profile of who, you know, the patient in bed three might be. But until you go and speak to the patient, do you really know them? And I think when we're relying only on that, as you said, quantified profile, you know that's really harming, the relationship with the [00:30:00] patient because, you know, like my surgeon said, you know, what's what's your quality of life today? Well, if you don't know, that I've got three very young kids, then are you going to be able to advise in the right ways? I told my neurosurgeon during the very first visit with him, and this was, I mean, pretty naive because I, I didn't yet have all of the knowledge on board to understand what we could include and control through the placement of the tumor, et cetera.

But I said, you know, doc, put me in a wheelchair if you have to, but I want to be able to still read a book. And I think that was an important, you know, if you don't take time to get to know who I am, then how's the doctor going to know that he should prioritize reserving as much of my kind of language and communication function as possible, whatever's within his control.

Michael Nathanson: Sure. Well, I can definitely appreciate that. So, Is there a specific way you want people to speak with you about your illness? How should people talk to you about your illness is the answer is, well, it doesn't matter just be natural or are there things that you can help teach us in terms of [00:31:00] how we can speak to people who have GBM or another really difficult, challenging illness?

Adam Hayden: Yeah, we are, we tend to be problem solvers. That tends to be the first mode that we jump to. We hear something's wrong. How can we jump into help?

Michael Nathanson: I call that the hero complex.

Adam Hayden: Absolutely you know, I think, understanding that quiet presence. It is much more powerful than we lend it credit too. So if you don't know what to say, that's okay.

You're not alone in not knowing what to say. Those of us living with it. We don't really know what to say either, but coming and being with us, that's something it's, it's interesting that how do you want us to speak with patients? The first answer is, well, don't be afraid of silence.

And I think, you know, there's so many cliché things, but I think are worth reinforcing, you know, that these kinds of platitudes, I tend to come from a place of projection.

So we'll say things like, oh, well this is all part of a plan. [00:32:00] That's pretty common. And folks who are inclined, I think towards some religious identification, not to pick on a population at all. But just to say that, I think it's, it's kind of part and parcel of having some sort of a faith that you want to believe that there's a plan and you're being used in some way to execute that plan.

My dad's clergy. So I've had plenty of people tell me that I'm being used as a tool in a certain way. I think man, be careful with that because then you're telling me that the plan was to give me brain cancer. The plan was to potentially cut my life short and leave our three young boys, without their dad in their lives.

So, just be careful of those kind of platitudes and the ways that we went to comfort ourselves. So it might be comforting to you to imagine that there is a grand plan that may not be comforting to the patient. So just really being aware of when you're projecting your own distress and wanting to comfort yourself.

And when you're, you know, really centering your experience [00:33:00] on the person who is in the hospital bed. That may direct us a little bit.

Michael Nathanson: Well, thank you for that. I appreciate that education because actually one of the questions I was going to ask, and I didn't mean it so much in a spiritual or religious way.

I was just curious how you would answer it, this, you know, just asking you to be the philosopher that you are, you know, why is this happening to you? But I think you're basically saying you don't really want to hear that kind of question. Yeah, which I appreciate that.

Adam Hayden: Yeah. I mean, I think, you know, oftentimes when we have these big why questions, you know, we're trying to figure out something. Wilfred Sellers is a philosopher who said, you know, that the purpose of philosophy is to figure out how things in the broadest possible sense of the term hang together in the broadest possible sense of the term.

And so that has always kind of stuck with me since I first read that. And, you know, I think we can ask questions about. How does this, how do we react to this? How does this change our meaning making in the world? What does that mean for me and my purpose and my goals and my objectives, all of that I think is [00:34:00] perfectly appropriate and good things to talk about, because it's like, well, Adam, if you're not going to get into a PhD program and do that for five years and then go and try and get on the job market, if all you take all that away, well, then what are you going to do?

And so that does. You know, that gets into some why questions, some objectives, some values and goals. And that's all very important that we talk about that. But I think in terms of looking for a reason, why Adam, did you get cancer? I'm not sure how productive that question is in itself.

Michael Nathanson: Thank you for that, I appreciate that. Yeah. Thank you. So now I'm going to ask, I'm going to ask another difficult question and I hope it's okay for me to ask these questions, because I really do want to be mindful, about our community and the way people do want to talk about their illness, understanding that it's probably different for so many people, but I want to ask you, do you think about your death often?

Adam Hayden: Yes. And I think, it's not a constant, it's something that I think ebbs and flows over [00:35:00] time and I'm not, and I probably couldn't point to the, you know, the signs that why it ebbs and why it flows. But yes, it is certainly on my mind and I will, so I will open up here. And so we are looking for a house right now and there's that financial toxicity is, a term that you'll hear in the cancer space. Just to, just to put a point on this for folks, is that my benefit plan my medical benefits through my employer, the benefit plan year turns over in July. I was diagnosed, surgery was in late June. I was diagnosed or rather late may diagnosis came in June.

So I had to meet, my, our family had to meet my out of pocket. And then just for surgery that happened in May and then all of a sudden, mid chemo and radiation, the plan year turns over. So we had to meet the out-of-pocket again. So that's, you know, within a couple of months of each other, we did an annual out-of-pocket max back to back, in addition to I couldn't work at the time. So thankfully I have long-term disability. So there was some help there, [00:36:00] but that's 60% of your salary is what comes out long-term disability.

So ask most folks could you give up 40% of your salary and live the same life. The answer to that for most folks is, well, no, probably not. And so brain tumors are expensive, and in fact, medical expenditures for brain tumors, it's about 20% more than what folks spend on healthcare annually. So it's an expensive disease, even with insurance coverage.

So that put our family in the hole, you know, I mean, my wife who works full time outside of the home, she had to significantly cut back hours. Cause I wasn't driving, I required daily trips to radiation. I wasn't really safe. Right. I mean, I've had epilepsy as a result of the tumor. So, it's tough to leave me alone.

You know, we've got nanny cams on the house, so Whitney can just make sure I'm not down somewhere. I can laugh about that, but it's serious at any rate. It's taken us a long time. We rent our home, that home we're in, I'm in right now. We rent this home, because there's a debt-to-income ratio stuff.

Right. It's tough. Yeah. So we finally have got ourselves in a position where we are looking for a home, which is [00:37:00] terrific but here's the reality. We told our realtor. That we need a home that if we had to move a hospital bed into the home in the future, home healthcare, even home hospice, that is a consideration. You know, people are like, well, I want to ranch on this size lot with this, you know? And we're like, well, we need room for a hospital bed. So, uh, in terms of thinking about death, sometimes I think about a big and sometimes I think about just the practicalities of do we have the space and the logistics for a comfortable dying at home?

Michael Nathanson: Yeah. Do you live in fear of it?

Adam Hayden: You know, listen, I'll tell you, the thing that I'm good at is talking and writing. Some people are great at archery, you know, and I'm good at having conversations. And the progression of this disease likely will impact my higher-level executive function, my ability to communicate and express myself.

So it's got a little bit cliché to say, it's not death, I'm afraid of, but it's dying. But I think that's, that is true. Uh, I just can't imagine, the person you're talking to [00:38:00] today, this is me. This is Adam. And so you take away my ability to articulate myself. That feels less like me. And so I am afraid of that.

Michael Nathanson: You have a blog that you, cleverly called glioblastology. Did you make that up?

Adam Hayden: I did.

Michael Nathanson: That's great, you've got to trademark that, that's very clever and you wrote about it, so I have annual MRIs. I assume you have them much more frequently than annually. How often do you have MRIs?

Adam Hayden: Every three months, currently.

Michael Nathanson: Three months. Yeah and you wrote that stable isn't as great as you think stable is the best possible outcome. And you talk about this concept of scanxiety. Another term you made up, I assume.

Adam Hayden: Well, that's, I can't take credit for that. That's in the brain tumor community and I, and I think it's spreading to other cancer spaces as well, but no scanxiety, we use it a lot, but I can't claim it.

No that's not mine.

Michael Nathanson: So that's just the concept that, Hey, look, it's good to be stable, but yeah, it's terrifying. Every time you go through this process.

Adam Hayden: Yeah I mean, brain tumors are [00:39:00] rare diseases. I mean, I think most folks with cancer generally, you're under some sort of surveillance if that's annual surveillance. Some people may be even spread out more than that. But there's, I think folks don't realize when you get cancer, even if it is totally gone and there's what we call no evidence of disease or NED. You know, folks in the world will call that remission. But no evidence of disease is the kind of the clinical term for it. But if you've had cancer, you might be able to go for 10, 20, 30 years. But there's always a risk that it could recur, and with glioblastoma, because it is very aggressive.

It's a near universal, rate of recurrence. I mean, you know, there are long-term survivors, but like you said, you know, 5% of folks, live five years or more. And now I'm in that 5%. So boy, that's tough to know that I'm a, such a small subset. I mean, we are so grateful for that. I mean, I've had this five years with our kids to see them grow up.

We didn't know if I'd had that time but yeah, every time [00:40:00] you go for an MRI, I mean, the purpose of that thing is to see what that tumor in your head is doing. So there just is the risk. That this will be the one that shows growth or something like that. And also, I mean, I want to highlight this too.

Is that an MRI scan, I mean, it's pretty uncomfortable. I mean, I think people realize it's like a loud machine. Yeah. But, you know, I have to get an IV and there's a contrast dye does push through the Ivy and I had this technique called perfusion that requires a really rapid, injection with an auto injector.

And so that's, it's uncomfortable. And every so often I'll blow a vein. And that hurts pretty bad. So, I mean, I think what we often don't talk about are just the routine of getting a scan of a changing out of your street clothes and putting on a gown that's really revealing and having an IV placed and getting in this machine for an hour that's loud and noisy.

So not only is it the existential concern of the cancer, it's also just that kind of stinks to go through the process of it on a regular basis.

Michael Nathanson: Yeah, sure. I do know [00:41:00] I in, I'm sure you do, and I'm sure you've read about all this. I mean, I actually personally know two people who have lived for more than 20 years with GBM.

Do you have hope that you'll live for 20 plus years that you could potentially be one of the, well, you're already one of the lucky ones, but ultra lucky ones?

Adam Hayden: Yes. That, well, I'll say this, I, you know, I'm, I'm pretty cynical and sarcastic just generally.

Michael Nathanson: That's all right. Be yourself. I think that's what we all want it. We all want to hear. Okay. So far you've been delightful.

Adam Hayden: Good, good. So Whitney and I, the thing has always been for us is that we don't need to live a year or three years or five years. We only need to live as long as the next treatment thing that's coming. And so I think we haven't allowed ourselves and maybe that's not the right phraseology. I don't think about 20 years of survival. I think about when is the next thing coming. What are the clinical trials that are on the horizon? [00:42:00] Because somebody who lives 20 years, that's not a big block of 20 years.

That is just this treatment to this treatment, to this treatment, you know, and you rack up 20 years in the process. So that's kind of been our mindset from the beginning. I think I'd rather be, I mean, in palliative care they say hope for the best and plan for the rest. And I think that's kind of our, our methodology too at home.

Michael Nathanson: And it does look like I read in one of your readings. It does look like you are taking good care of yourself. You write about these so-called 'you might as well' sentiment. And you commented that people might, might have comments to the effect of quote "you have brain cancer, have some ice cream you might as well." In that post, you say you resisted the idea that serious illness affords an anything goes attitude and paradoxically perhaps I suggest that the opposite is true. Serious illness demands, more rigor and discipline. So you're living a healthy life?

Adam Hayden: Yes. I mean, as much as I can, you know, it's [00:43:00] so this is good. This conversation thread in particular, well, the whole time has been terrific, but this right here, I think is good because this is going to, this is a hot button issue with patients, because so there's a couple of things happening here. One is that was actually a doctor who told me that, you know, you get weighed all the time, just regular blood work and what's your weight and all that stuff, uh, through chemo, especially cause you're looking for, you know, that what are the toxic effects of this?

And, you know I've always been kind of a skinny guy. And I was, I was getting skinny, with chemo and a doctor said, listen, man, you know, you got brain cancer, go home and eat some ice cream. And it felt so dismissive to me.

Michael Nathanson: Oh yeah it pisses me off to hear you tell me that. That pisses me off to hear you say that. When you tell me that story.

Adam Hayden: Yeah. And that was my reaction as well. There is certainly, I mean, there are lifestyle factors. I mean for everybody, right? I mean, for, for just any normal person with, or without illness, I mean there is science and it isn't totally settled, and nutrition science itself is kind of a mess sometimes.

Cause you have to rely on like [00:44:00] observational studies and you can't, you know, you can't lock people in a room and feed them the same diet for a year and see what happens. So you rely on their self-reports and stuff like that and patients it's tough because there's all of these, whether it's the keto diet, which a lot of folks are looking for efficacy and cancer space around the keto diet and it's a lot of conflicting evidence. And do you really want to put some, somebody on a restricted diet, for example, while they're living with a serious, if not terminal illness. So it's all really a lot of patient politics come to play here. But yeah my, so I'm, I'm an old punk rock dude. I was in a skate punk band back in high school and for whatever that's worth. And I, I said in some blog posts, I said the most punk rock thing I can do is get a good night's sleep. But I believe that, I mean, I think in the face of serious illness, sure. I could just throw everything out the window and kind of do what I want. But it's almost like a middle finger to the disease.

If I say I'm going to try to be as healthy as I can be despite you brain cancer.

Michael Nathanson: Fascinating so would you be willing to share how you speak to your children [00:45:00] about your experience?

Adam Hayden: Absolutely. Yeah our oldest, you know, I wish he weren't so damn smart. I guess you kind of forced the conversation on us a little bit.

No I'll tell you we we've, I think we've needed to be honest with the kids. I say it's both our approach, Whitney and I, you know, we want to have sort of independent, kids in the world and we want to prepare them even before any sort of diagnosis that I had.

I mean, it was just important to us as parents and we are, you know, we're parents, I think typical for our ages, we're sort of in the elder millennial class.

So, you know, I mean, we had kids a little bit later in life and I think because of our life experiences, you know, Whitney and I are like, yeah, we want to have independent kids and we want them to be able to, you know, know what they want. And get that on their own, you know, I mean, just stuff. Right. And so we are honest with our kids. After a surgery, I had about 40 surgical staples in my head. I mean, you mentioned the tumor was big. So the amount of skull they had to remove was big to get a big tumor out of my head. And that required about 40 surgical staples on the top of my [00:46:00] head. And so when the kids came to see me in the hospital, you know, you can't really cover that up.

And so we knew the kids were going to see it and we would have to say something to them. In the moment I told our oldest, I said, listen, what happens when you skate in your knee? And we walked through, you put a band aid on it. A scab goes over that eventually there's new skin. So that is a way that we help to explain the immediate kind of trauma of surgery, that this will heal. So that was kind of an entry point for that conversation. I began to volunteer with National Brain Tumor Society pretty quickly into my illness. I mean, not right away, but within the first several months we were starting to do some National Brain Tumor Society stuff.

And so we had some swag around the house, and our oldest as he learns to read, he started to like piece together, brain tumor, and what's a brain tumor? And we were calling this thing on my head, a brain booboo. So the first thing we did is just connect the dots of the brain tumor that you're reading on this stuff is actually dad's brain booboo.

And then after another couple of [00:47:00] months, it was just a connect another dot to say, now this brain tumor, in fact, as a brain cancer for dad, and that means that he may not live to be an old man, like your grandpa. And we could look at pictures of family on the wall. In fact, my wife's dad and she's spoken about this publicly, so I'm not disclosing anything that would violate her privacy, but her dad died when my wife was a teenager.

And, but we still talk about. Grandpa David, you know, Grandpa David plays a role in our life, even though he's not with us. So we could talk about that with Isaac to make the connection for him. And I think that that's both using his experience, but trying to be age appropriate, but not holding back. And so that's, that's how we had that conversation with him. His younger brothers, seven and five, they sort of absorbed that they weren't that old at the time when we had these conversations, but I think they absorbed that through Isaac and for right or for wrong, you know, I think this is just how siblings, how it goes, but you know, they look to Isaac a lot, uh, for direction and, and what do we [00:48:00] do and how do we understand what's happening?

And so that's a burden that is on Isaac's shoulders but we've just tried to make them a partner in the process. And to be honest with him.

Michael Nathanson: Yeah you've been kind enough to share with the public, some of the ways your children have interacted. I think at one point you might have posted a picture that at least one of them drew and it's again, it's just, I can only imagine how difficult that must be to have those conversations. Your wife, I got to meet your wife once and she seems pretty awesome. The way you talk about, or it sounds like she's been a real rock for you.

Adam Hayden: Yeah, absolutely. I mean, she is, you know, my wife is, she's just my best friend. I mean, I think this is, you know, everybody, I mean, so my parents were high school sweethearts, so that's a different experience. I mean, 15 and 16 and they were about to celebrate 40 years. So they, so you know, that model can work, but Whitney and I have a different model, which is that, we were in serious relationships through our twenties that dissolved.

A positive development in each of our lives but because we got together now, we've actually known each other for decades, [00:49:00] in fact, uh, but when we got together romantically, we were in our late twenties and we have sort of been through we know what we don't want now. And so we knew what we wanted and it turned out to be each other.

So we really are, are each other's best friend or at least she's my best friend. I don't know. I hopefully I'm in the top five on her list. But she is a champion and an advocate. And this woman I've said this a lot but I'm going to say it again. Cause I think it's funny. She works in our cities county hospital.

It is a level one trauma center. My wife is an occupational therapist, so it helps folks with activities of daily living and stuff like that, but because of the nature of her work, I say, if you're not shot stabbed or thrown off a motorcycle, it's tough to get sympathy from my wife. So she is tough.

She's hard-nosed but that's exactly what, what I need. So that's good.

Michael Nathanson: And again, speaking about your community, that's been supportive, you did mention National Brain Tumor Society. And I can't resist the giving you the opportunity to speak maybe a little bit more about it and full disclosure to our audience.

I too am [00:50:00] actively involved and have been for at least 10 years with the National Brain Tumor Society but Adam, you want to speak a little bit about MBTS?

Adam Hayden: Absolutely. Yeah. I mean, this is the organization that I needed in my life. There are a lot of brain tumor non-profits and I think this is that, I mean, you know, you can never have too many communities of support in serious illness spaces, but the one that speaks to me is National Brain Tumor Society.

I mean, there is a concerted effort to get better treatments and ultimately deliver on a cure. This is a nonprofit that is just laser focused on the science. And I think that's what first attracted me to National Brain Tumor Society is that they made really big audacious pledges of both audacious of money investment, and audacious in goal to defeat glioblastoma and they've put millions of dollars toward that effort.

So I've been a proud National Brain Tumor Society advocate for just about as long as I've been living with this disease. [00:51:00] And my involvement has only increased year over year, over year. So in the beginning, I mean, I think there was some support materials, the brain tumor experiences, a piece of the website at braintumor.org. You know, where there's based on stage of treatment, if you're at diagnosis or you're at surgery, et cetera, there's a really helpful resources for what you might want to ask your doctor about. So perusing those materials, that was sort of my like, oh, this is really helpful and really good stuff but when I was able to attend their annual advocacy day for the first time called Head To the Hill, where you go to Washington DC, I'll just tell this briefly, when Whitney and I walked into the hotel lobby, our very first time to the Head To the Hill, I looked around and what I immediately noticed is how many other people had craniotomy scars, surgical scars on their heads that look like mine.

And that was, that felt like a big hug. And I think if you've not. You know, if you've not been through something like that, any sort of surgery but if you get a very distinct scar, you feel a little alone in that. I mean, I don't know if it creeps people out or, [00:52:00] you know, whatever. I mean, it's not, I'm not deformed, but you can tell something has happened, but walking into a space where hundreds of people have this thing, it's like, oh my gosh, I am home.

And then to be able to take a message to Congress, I mean, here's something that we've done, is that we have consistently helped to increase the budget for the national institutes of health year over year, over year. We have increased DOD funding for their peer reviewed cancer program. Year over year, we all joined together to pass the Childhood Cancer Star Act.

That's so that's our DNA on that so it's just so powerful, these days I'm one of the co-facilitators with my dear friend, Lisa O'Leary. We co-facilitate a virtual support group, the National Brain Tumor Society that meets monthly I've written blogs for MBTs. I've attended quarterly research meetings with them from the patient perspective.

So yes, terrific organization. And this is the last thing I'll say is that the CEO of MBTS, David Errands. David is not a CEO from afar. I mean, its not uncommon for me just to be doing the dishes [00:53:00] after dinner and at 7:30 I'll get a call from David Errands and it'd be like, Hey bud you know, I'm driving home from work. Just wanted to check in. So that's the type of leadership at MBTS, and just could not be more proud of the organization. We host an annual fundraiser here at home for MBTS and, yeah, I'm all in,

Michael Nathanson: Right. The, a tumor takedown.

Adam Hayden: Tumor take down tailgate. That's right.

Michael Nathanson: And I just want to say that, that one of my, well, one of the things that I'm very proud of in terms of my own service to what MBTS is that when I served as the Board Chair, bringing David Errands on as the CEO was a big part of what we do we were doing to move the organization forward.

And I think of hiring David as one of the great accomplishments of the organization while I happened to be serving on the board and very proud of everything that he does for the organization and for the community. And I really appreciated your thoughts, Adam, about all the work that you and the community have been doing in terms of [00:54:00] advocacy, because advocating for more and better and more targeted spending from the government combined with industry combined with the nonprofit space, it really takes all of those things in order to be able to ultimately, fund the kinds of therapies that will ultimately lead to a cure.

So I really appreciate your thoughts about MBTS and I'm going to shamelessly plug them @braintumor.org. A great organization. So Adam, I just want to, I'm going to ask you one more question and then we're gonna move into our lightning round. But you do spend a lot of time talking about palliative care and you're very active in that space as well. And I wanted to just give you a chance to speak to it briefly. You wrote earlier this year, I believe probably it was January of this year. You wrote that patients are told not to throw in the towel. Don't lose hope, hold up for the miracle. But when we frame cancer survivorship by a relentless [00:55:00] battle, we award the wrong priorities.

Instead, we should celebrate reconciling the plans that we had for our lives, with the reality that we may need to adjust our goals. Maybe the miracle is not the lifesaving treatment breakthrough, but instead it is the breakthrough of fresh perspective that asks honestly, How would I like the completion of my life to look and not, what can I possibly do to extend it?

So, you know, given your comments about the hope that you continue to have, I do want to give you an opportunity to speak a little bit about your advocacy in the palliative care space.

Adam Hayden: Yeah. Terrific. So I think this is one of those areas where I always like to kind of claim upfront that whatever language really a patient identifies with then that is sort of theirs to own. So I have been critical of kind of the battle or warrior theme, motif, metaphor, whatever, you know, I think that [00:56:00] it's not my preference to say that we are in a battle or a fight or a war with cancer, because that assumes that if I do die, then somehow I haven't been fighting hard enough.

And yet I know that that being kind of a warrior, a brain tumor warrior adds a lot of power, to folks in the community. And I want, so that is, that is up to the patients to claim.

So when I'm critical of that metaphor, I just always like to take an opportunity to say, I don't blame anyone for sort of owning that language if it speaks to them. I'll just say that quickly as a qualifier.

Now I'll pivot to the palliative care question, which I really appreciate the ability or, or rather the opportunity to speak to that. You know, I think the first thing is to say palliative care certainly is not hospice, that those are often conflated and patients will say, oh gosh, you're going to call them palliative care.

Does that mean that it's the end? And palliative care certainly does not mean that the first time that I met with palliative care, one of the very first [00:57:00] questions, the physician had reviewed my chart. He saw that I had been to dermatology a couple of months before for some mild eczema and I was prescribed a topical steroid and the palliative care physician said, Hey, is that topical steroid working for you before looking at something else.

And I love that story because people think palliative care means end of life. Well, palliative care just means taking care of sort of the whole person. So sure, I've got brain cancer, but if my skin is itchy, then that's not a good quality of life. So I think that's a good example. Palliative care is about an interdisciplinary team that really wrapped their arms around the patient.

So whether that's a social worker or a chaplain or a psychologist or a physician, it's about how can you live as well as you can for as long as you can but without either of those infringing on the other, that's how I like to describe palliative care. And I think it's great for things like brain tumors, because it isn't only our cancer, but it's all of this neurological stuff that we're dealing with as well. So a complicated disease.

Michael Nathanson: Adam, I think I could talk to you all [00:58:00] day long. I just, I have so much to learn from you. And you said it's up to me to decide, so I do like the term brain tumor warrior, although I absolutely can appreciate what you're saying about the concept of a battle, but I was going to say as a fellow brain tumor warrior, at least from my perspective, I think I could spend the whole day talking to you. So I do have, I have to move forward though. And what I do is I ask all of our guests some of the same questions, and I'm just always interested to hear how people with different perspectives and different backgrounds, but who have lived extraordinary lives, answer these questions. So I'm going to begin with our key learning segment and ask.

What's been your biggest learning opportunity?

Adam Hayden: Yes. So I think the biggest opportunity is gosh, I think getting onstage at Endwell, we've talked about that a couple of times, that was really a pinnacle moment for me. I mean, that was like a theater full of 700 people [00:59:00] and it was being live streamed out.

So as I understand it, that, you know, some thousands who were watching a live stream, so I think. It was a learning opportunity because it taught me to take my story, which had been really small, kind of small setting and to somehow make that applicable to a whole lot of people. And the reason that was a learning opportunity is because in patient advocacy, you need to know your own story really well, but you have an obligation to also represent the entire disease community. And that was the first time that I really got to think about that in a serious way.

Michael Nathanson: Yeah. And I highly recommend Adam's speech. It's delivered like a Ted talk it's as good as any Ted talk. It was extraordinary. I did watch it. And Adam, I don't know if you have a website for it, but I, I just Googled Endwell Adam Hayden and found it pretty quickly.

Adam Hayden: Yeah. That's a great way to get to it. I mean, I've got it linked out on my blog, but, Yeah, Adam Hayden Endwell and you'll find it.

Michael Nathanson: Adam, what are you most proud of?

Adam Hayden: Yeah. This growing relationship with these boys, that, you know, I mean, I worry [01:00:00] about how my decline could ultimately impact them. But we have been so honest and forthcoming with them and, you know, Whitney and I are aligned.

So I'm just proud that I think we're putting those boys in the best possible position to handle something that will be very difficult.

Michael Nathanson: Can't say I'm surprised to hear that answer. Who are your key mentors?

Adam Hayden: Ooh. Good one. Gosh. Yeah. So I'm going to say, a couple of academics I'll start with, one is Havi Carel, and Havi Carel is a philosopher, but who is living with a respiratory disease that ultimately will be life limiting Havi Carel has taken this really abstract philosophical idea, phenomenology, which is a gold star word but she has made it real. And her writing is about using that philosophical framework to help other patients. So I've read a ton of Carel's work. I even emailed her and she sent me a signed copy of one of her books. So she's a mentor.

Elise Tarbey a [01:01:00] PhD researcher in nursing science. She is, I read everything that she does. She talked a lot about existentialism and, and so that's, you know, wrestling with our own mortality. But because she's coming from a nursing science perspective, it also combines kind of the clinical landscape with these like big life questions. So those are, those are two, academic influences that have shaped so much of my thinking. Shoshana Ungerleider who's the founder of End Well. You can see a theme here. Shoshanna's terrific. And she is always looking for new ways to promote conversations around the end of life and doing it in a way that is approachable and is warm and can be funny. Yeah, so I think those three, those three folks are all mentors to me.

Michael Nathanson: And, And what will be your legacy?

Adam Hayden: Oh, good, man. You're good at this. I'll tell you. I thought my legacy was in the world. I thought it was for a long time. I was, I was traveling, giving a lot of talks, meeting a lot of people, and I thought that's [01:02:00] my legacy. I was on an especially busy travel stretch in the before times. Of course, pre pandemic. I got back from a long stretch of trip and Whitney sat me down and she said, your legacy is not in the world. Your legacy is right here at home with our three boys. So when I think about my legacy, it is shifted, over the past several months or, or a year or so. And what I think it is is that I want people to remember the stories about me. And I want those to be funny and heartwarming. So if somebody, a generation or two down the road has a funny heartwarming story about Adam then I can't imagine a better legacy than that.

Michael Nathanson: Love that, love that great answer. I had the privilege of interviewing my son for a, a prior edition of Seeking the Extraordinary. And my son suffers from congenital heart disease and has had four open heart surgeries. And I asked him this question and. Like you, he is a philosopher. Like you, [01:03:00] he is off the charts brilliant. Like you, he is off the charts articulate.

He actually, his answer, your answer reminds me to some extent of his and the way he said it was, it's not gonna be a paper legacy, meaning it's not going to be a legacy about all the things that I did or published or wrote or said. I think he has a similar philosophy. I appreciate that answer, Adam. So lastly, we go to our teaching moment and I'm going to ask you three questions and seek quick answers from you if it's possible, what single habit, technique, or tip can you offer our audience that has helped you be your most extraordinary self?

Adam Hayden: Get it out of your head and onto the page. We all wrestle with this stuff in our own brains and it keeps us up,

at night, just carry paper. And when you got a problem, a flash of brilliance of something you're working on to put it on the page and get it out of your head,

Michael Nathanson: Love that and I can totally relate to that. Adam, what's the [01:04:00] best advice you've ever given to or received from someone else?

Adam Hayden: And that's the one. So you said given or received, if I say something I've given, I don't want to prioritize myself. So best thing I've ever said was an accidental thing, but I said "face fear with familiarity," and I think anything that is too big or too scary or too intimidating, that means we just haven't learned enough about it.

Michael Nathanson: I may steal that. That's excellent. And lastly, do you have a personal mission?

Adam Hayden: Oh, it is, you know, I, I say these three pillars show up everywhere, which is philosophy, illness and healthcare. So if there's, you know, if it is a personal mission, it's got to have something to do with those three pillars, I would think. Yeah.

Michael Nathanson: So Adam, you you've said a lot. I'm guessing that many members of our audience will be interested in learning more about you. How can they follow you on social media or otherwise.

Adam Hayden: Yeah, so for right or for wrong, I am my Adam Hayden, my name on just [01:05:00] about every social platform. So I'm pretty discoverable on social media.

A lot of my stuff is public. My blog. It's sort of more than a blog. I mean, I've got all my articles and stuff linked out there too. So that is, you already said it, but its glioblastology.com. So that's a great kind of headquarters for Adam on the web.

Michael Nathanson: Yeah. Thanks. Thanks Adam. And I want to give you an opportunity to any parting words. You've said a lot. Anything else you'd like to get out there?

Adam Hayden: Oh, you know, I mean, I just think, gosh, illness is such an opportunity, to just confront that stuff about what matters to us. But you don't have to wait on illness to do that. So maybe it's by looking yourself in the eyes in the mirror, maybe by gazing deeply into your partner, maybe by looking at kids, if you have kids in your life. But just don't be afraid, to remind yourself that this life is fragile. And you know, that's so cliché, isn't it, Mike, but I think that is, I just encourage folks. Don't be afraid, to really get serious. About how much time you got here [01:06:00] in the world and make sure you do something every single day, that's going to get you toward, the life that you want to have in the end.

Michael Nathanson: Thank you, Adam. Yeah, you and I talked about philanthropy and National Brain Tumor Society. And I just want to reflect on the true meaning of that word and the concept of love for people. And I want to express the love in my heart for you and other members of the brain tumor and brain cancer community, as you point out.

And just so grateful that you're willing to share your story and your knowledge and just help educate the rest of us, about brain cancer, but also about illness and healthcare, as you said, generally, thank you so much.

Adam Hayden: Thank you for the opportunity. I mean, it really is an honor because I know that I'm, I mean, goodness, I didn't even know that you interviewed your son, but I know I'm on a roster with some very impressive folks. So I'm honored to be invited into this conversation,

[01:07:00] **Michael Nathanson:** They're all impressive including you, ladies and gentlemen. That is the extraordinary Adam Hayden.

And thank you to our sponsor The Colony Group. The Colony Group is a national wealth and business management company.

with 15 offices across the country. That itself seeks the extraordinary as it pursues its unrelenting mission of providing clients with peace of mind and empowering their visions of tomorrow.

To learn more about The Colony Group and how it manages beyond money visit www.thecolonygroup.com. You can also follow the colony group on LinkedIn and on Twitter @colonygroup.

For Seeking the Extraordinary I'm Michael Nathanson. Follow me on LinkedIn and Twitter @nathanson_MJ, and learn more about my ongoing search for the extraordinary.

Disclosures: The Colony Group, LLC ("Colony") is an SEC Registered Investment Advisor with offices in Massachusetts, New York, Maryland, Virginia, Florida, Colorado, Connecticut, California, and New Hampshire. Registration does not imply that the SEC has endorsed or approved the qualifications of Colony or its respective representatives to provide advisory services. In Florida, Colony is registered to do business as The Colony Group of Florida, LLC. Colony provides individuals and institutions with personalized financial advisory services. This information is general and educational in nature and is not to be construed as investment, tax, or legal advice. Individuals should seek advice from their wealth advisor or other tax advisors before undertaking actions in response to the matters discussed.