Havi Aunts and Uncles Selects

Lower Thirds:

*Jacob & Erin, Leah & Mike*

*Aunts and Uncles of Havi and Kaia*

*Havi lived with and died from Tay-Sachs, age 2 ½*

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| 1 | Title: *When I think about Havi, I think about the purest laughter and joy and heart.*TC: [00:03:01:04]The aunts and uncles -- who moved to be near their little niece, Havi, diagnosed with a fatal condition, and her parents Matt and Myra -- introduce themselves and share a sampling of their love for and memories of Havi. "She had a way of reminding us all of what the most important things are. .. She could just captivate the room." https://youtu.be/f11amXvJwNo**Jacob:** All right. My name is Jacob, and I am Havi and Kaya’s uncle and I am Myra’s brother and Matt’s brother.**Erin:** My name is Erin, I am Jacob's wife, and Myra was my best friend at Dartmouth. And I'm Hav’s and Kaya’s aunt.**Leah:** I'm Leah, I am Havi and Kaya’s aunt and Myra and Jacob’s sister, and Matt is my brother-in-law.**Mike:** I'm Mike, I am Hav’s uncle, Leah is my wife, and Myra and Matt are my brother and sister-in-law.**Interviewer:** So tell me about Havi, just start gushing about Havi [00:04:00:05] in no order. When you think about Havi what words or scenes come to mind?**Leah:** When I think about Hav I think about just the purest laughter and joy and heart. Yeah, just, just a purity that is so good and deep. **Jacob:** Yeah, when I think about Hav I think about sort of this angelic figure that I got to know in real life and like Leah said there's a beauty there but there's also just this sort of [00:05:00:04] -- I don't know, just the sort of other worldliness about Hav that was so such a pervasive feeling.**Mike:** Hav is, like Leah said, her laugh is just like constantly running through my mind and I also -- I think for all of us there was something about like nature that I think a lot about with Hav, the wind we talk a lot about or the ocean. So there's some sort of nature like feeling I have all the time when I think about her.**Erin:** Yeah, I think she's just this total wonder both when she was here with us physically and also now to what Mike was saying. [00:06:00:05]. She's so stubborn, slept maybe five hours and rancour with us all the time every dinner and we would -- I think some of my most vivid memories we'd be sitting there having a very adult conversation about a hard day at work or a hard case that Mike was working on and Hav would just sense and read the room and erupt in laughter and we would all stop immediately what we were talking about and it just completely faded away, it was so unimportant and Hav always had this way of reminding us what the most important things are. She was just a total wonder.**Leah:** Yeah, I think captivating too is -- as [00:07:00:06] Erin was just saying, like, everyone stopped whenever Hav did anything, you know, she could just captivate the room and – yeah. |
| 2 | TC: [00:15:00:04]Title: *We all had imaginations about what it would mean to be an aunt and uncle; when we learned her diagnosis, it was a clarification of priority.*Aunts and uncles of a little girl with infantile Tay-Sachs talk about how their dreams and priorities shifted with the diagnosis. "There is a part of this that they (the parents) were experiencing that we'll never really understand but we got as close as is possible." https://youtu.be/BS23wzgiyw4**Jacob:** Oftentimes people in thinking about and asking about our sort of family’s closeness try to ask some version of the question, well, was it really like this before, were you as supportive before, did you talk as much, would you have made the same decisions you prioritized the same way, and the truth is I think all of us and I'll speak for myself but I think all of us were just overjoyed when we learned that Hav was coming into our life, our collective life, and we all had imaginations about what it would mean to be an aunt or an uncle and what it would mean for our parents to be grandparents and how we would relate to each other in that capacity. When we learned about her diagnosis [00:16:00:05] there was no change in our closeness, or there was no change in who we were or how we loved each other, or how our lives would always be sort of together, but the prioritization and the North Star for all of us became that much more clear. And so, it became even more so collective because we needed each other's support and love and it would have -- it was, it would have been, I don't know a different version of that, but it wasn't a change in closeness, it was just a clarification of the priority. That’s how I would think about it.**Leah:** Yeah, I agree that we were always incredibly close and a part of each other's lives. Of course, we weren't living with each other so there's a different dailiness. But [00:17:00:08] when you ask about did it feel like the diagnosis was happening to all of us collectively, I think that's a hard question to answer and in some ways I think it really did feel like it was happening to all of us as a unit and simultaneously, I think there is this piece that is uniquely Myra and Matt’s experience with that that we’ll ever, like, fully understand even as much as Hav feels like all of ours and as much as we feel kind of interchangeable with Myra and Matt and each other. I think that's -- it's really hard to come to terms with the fact that there is a part of this that they're experiencing that we’ll never really understand, but I think it gets pretty as close as it possibly can [00:18:00:04] to feeling like it was happening to all of us when the diagnosis -- when we learned and kind of the whole -- her whole journey of living and dying.**Mike:** I don't think I could say it any better than that. That I think that's exactly right.  |
| 3 | TC: 19:40Title: *It’s been a lifeline to have each other.*The Aunts and Uncles of a little girl with infantile Tay-Sachs -- who moved to be near and support the family -- share how they have been able to support each other. They elected to live together near their niece and her parents. Yes, it is a very unique situation. AND the way they describe the rhythm between themselves, how they show up for each other, is an inspiration for any group of aunts and uncles who circle the bandwagons with a shared purpose. https://youtu.be/QD0CELxn3BA**Leah:** Well, it's been a lifeline to have each other. Mike and I were talking about this that to be able to live with our counterparts who are related to Havi and to Myra and Matt in the exact same way that we are and experiencing the same journey, that's been a lifeline. And when we were thinking about [00:20:00:04] – I don’t know where I was going with that. Yeah. In a word, a lifeline.**Erin:** Yeah, I mean like, we laugh when Jacob asks Leah all the time, like, did you ever think we'd spend this much time together in our adult lives and to this day it's, like, the four of us have lived under the same roof for the last year and --**Jacob:** More.**Erin: --** more and it has been, like, it has been the most beautiful, easiest possible thing, which is unbelievable to say out loud that, like, we both been really true to our relationships with our partners but to each other, and we've been in this incredible rhythm where we, like, no, I feel when the other needs about space [00:21:00:05], or when there needs to be support because someone is feeling like they're picking up the slack a lot maybe around My and Matt and so the other one or one of us will do more around the house and there's just this really incredible, like, the only word I can think of is rhythm. We just really have -- it's just been this beautiful dance where – and a connectedness that maybe that feels different for me. There was always this closeness but there is just this -- when I think about who, like, protect -- when I think about who my protectors are or who will show up for me and for us, Mike and Le are who I think about immediately. |
| 4 | TC: 22:20Title: *Moving to be with our niece and her parents. (COVID made it easier to relocate). It wasn’t straightforward but it was clear.*The Aunts and Uncles of a little girl with infantile Tay-Sachs -- talk about the decision to move to be near and support the family; initially it was just about getting there to support post diagnosis and then they stayed. "Of course we were going to be here for as long as we needed to be. All of our stuff is still in a storage unit." All the employers understood AND Covid made it easier to relocate. "It's hard to be the aunt and the uncle in terms of this disconnect between internally how close we feel to it and externally how that role is perceived." https://youtu.be/zjRBqKUV3\_s**Mike:** It definitely wasn't a formal decision to move to Massachusetts, I mean, I think Leah and I -- I mean, all of this was kind of happening at the backdrop of COVID to where Myra and Matt and Hav and Jacob and Erin spend a lot of time together on the Havi moon and Tomales Bay and Leah and I weren't able to get out there because of it and our top priority was let's just get to Boston [00:23:00:09], we need to get there, and we were working both remotely at the time and so it was not a problem to just get up there. And then we were just, like, we're just going to stay here as long as we possibly can and that's been like a year and a half at this point or something, which is unbelievable, but I think -- I don't think it was a – and you correct me if I'm wrong, but I don't think it was a decision, like, we're moving to Boston or we're moving to Massachusetts from Texas, it was we need to be immediately close to them and with them and in a way that we aren't -- even that we're talking every day in a way that we aren't when you're just in person living with the person or living right next to them and being able to be in person with them.**Leah:** Yeah, we had been in Dallas. Havi was diagnosed in December and – of 2019 and we got to call learning that diagnosis [00:24:00:05], I think Jacob and Erin were already in Boston with them visiting and there had been a lot of concern leading up to -- in the past couple of weeks leading up to this final diagnosis. And we got the call, I think it was on a Tuesday, and we were on a plane the next morning or later that afternoon, I can't remember, kind of an indefinite amount of time to be in Boston. And then, as Mike said, over the next few months -- well, so we were kind of going back every other weekend and then in March when COVID got really bad, we -- I was feeling a sense of panic of do we need to get in the car and drive from Dallas to Boston to be with them, like, we’re going to get stuck here and never see Hav again, like, is the world shutting down. And so, as quickly as we could we, it wasn't even a decision that we talked about, we just figured out how to get a flight [00:25:00:06] and be in Boston, and then the amount of time that we spent here and what apartment or house we lived in together kind of evolved over the last year and a half. And, it was a no-brainer, of course, we were going to be here and for as long as we needed to be.**Jacob:** I mean, all of our stuff is still on a storage unit in San Francisco. But yeah, this notion of a no-brainer to all be together, that is definitely clear in what happened but I will say it felt like every day there was something that we had to move out of the way, logistically, or administratively that became so easy to say what's the most important thing and the most important thing was always being there for Hav and My and Matt [00:26:00:05] and then eventually Kai and yet there's a lot of stuff that you have to move out of the way in order to make it happen. And so, I just cherish that we were aligned on what the most important thing was and that then made all of the stuff easier, but it wasn't straightforward, especially with the backdrop of COVID but it was clear.**Interviewer:** How was it with your employers because I think I'm thinking about people watching this and #[26:37], okay, well, an employer is going to be much more understanding and lenient of the mother or the father, but I'm just an aunt or I’m just the uncle, I mean, you know, what I mean, like, how did you -- and you may have to situate this in COVID because, but did you go to [00:27:00:03] your employers and say, this is what I need to do and how did you negotiate this with your employers?**Erin:** I think we're all, like, took the same approach which we were just really straightforward and honest and communicated early and shared what was going on and, of course, COVID helped us because everybody was out of the office and working remotely, at least in my case, and I feel we all sort of had similar experiences and that all of our companies and employers were so understanding and supportive and almost at times helped to move some of those logistical or administrative things out of the way so that we can go do this, and we're lucky for that. I know that not everybody has that flexibility or that [00:28:00:04] relationship with their employer but it really made this possible. So --**Leah:** Yeah, I feel really great. All of our employers have been very understanding, and I think, speaking from my own perspective, I think it's also because it didn't come as a surprise to my supervisor that family is so important to me because, kind of going back to what we were talking about earlier, we've always been this close and so the people I work with and that I'm in school with know all about my family and know how important prioritizing family had always been even before there was ever concern about Hav, and I work in a relevant kind of in speech language pathology and pediatric speech language pathology, so I -- when we did start having concerns I was also talking to my [00:29:00:05] colleagues and my classmates about some of the concerns we were having and so they were kind of aware. But I think it made sense to them that this is what we were all doing because they understood our relationship with Havi and with Myra and Matt and our family. And I think that it's hard to be the aunt and the uncle in terms of this disconnect between internally what -- how close we feel to it and externally how that role is perceived. |
| 5 | TC: 30:15Title: *There is not adequate grief support for aunts and uncles.*Aunts and Uncles of a little girl with infantile Tay-Sachs -- who moved to be near the family -- talk about how little grief support there is for family beyond the nuclear parent-child group, including and perhaps most especially after the child dies. https://youtu.be/C5BwTPycmEMErjn: People or society is not good at talking about grief and knowing how to support grievers or loss and death, and then you layer on the fact that we are aunts and uncles and not necessarily parents and the already limited support that is available and is decently helpful then just lessens even more further for us. And so, I think when I think about who my support was and who I turned to it was our family and [00:31:00:04] not other people at our community or it was honestly CPN, like that. I -- it is unimaginable to me what the last two years would have been if we did not have CPN and all of the incredible people that came and come with it.**Interviewer:** I mean, it is a thing, like, there's nothing for aunts and uncles, I mean, there are no support groups. Whatever support groups exists exist for parents. And when parents are fortunate enough to have a family like you, and I think about Deirdre and my siblings and there's nothing for grandparents either this happened to you too and it's happening to you [00:32:00:05], it's happening to you and there's nothing.**Leah:** Yeah, I think some of that pressure transition back into regular work schedule and return to normalcy feels even more exaggerated for us. I mean, it's harder to actively choose not to do that because there's less understanding from the outside world and employers as supportive as ours are. It's just different than being parents.**Jacob:** I do think that somehow remarkably we've followed My and Matt’s lead in learning and understanding and trying to learn about grief and they've modeled such an amazing and open and hard, impossibly hard approach [00:33:00:09] to actually learning about grief and whether it was you guys in CPN or Dr. Joe or sort of the range of folks that My met actively sought out. I think we've engaged around a little bit of the necessary sort of study of grief and that's not something that I would have thought about before and it's still so absurdly underdeveloped and under-supported, but My and Matt made it apparent to us that they were going to learn all they could about how they were feeling and so that we should do the same, which I think opened up new channels in our relationship and our support and our [00:34:00:14] grief. |
| 6 | TC: 34:20Title: *Grieving together but focusing on Havi’s parents.*The Aunts and Uncles of a little girl with infantile Tay-Sachs -- who moved to be near and support the family -- speak openly about finding the balance between supporting the parents and checking in about their own grief, and about getting coping energy from each other. "We made a conscious decision to be in the support role." They also take their cue from the parents who speak openly about their grief and the grieving process. https://youtu.be/Mh3z77fXtUALeah and I, we'll have conversations about it where it's a particularly tough day or we send pictures to each other a lot of Hav and sometimes a particular picture just hits you in a way where it's just a rush and trigger something. So I think we -- I mean, Hav is constantly around us in the most amazing way, but there are these [00:35:00:15] waves that hit you, and I think we do a pretty good job. I mean, I think it's important. I think we all think it's important to talk about it and not let things go unsaid. I think we all want to know how each other are feeling and so we can be there for each other. And I think living with each other for the past year and a half you now don't need to always say things to know how the other is feeling and so there's some reading body language and just understanding, but I think it's expressed a fair amount.**Leah:** Yeah, I think that we still -- even though we know how important it is for the four of us to support each other uniquely because so much of our energy is spend taking care of Myra and Matt, I think we still don't [00:36:00:14] do the best job of, like, really checking in with each other on how we're feeling personally irrespective of what we can be doing to help support Myra and Matt. I feel some of that gets pushed aside a little bit and I don't necessarily know if I want that. I don't know how to articulate that totally but sometimes it feels like we don't explicitly check in about how we are feeling with our grief.**Erin:** I also think like that. There's both so much like unspoken communication and understanding just because of the way we've lived and been together the last year and a half. And also, I know if I'm having what feels like a crummy day [00:37:00:15] where I don't feel good but I know Lou is feeling good and he is able to laugh and feel like herself and then that both makes me feel really good. And also I want that for her or -- and so both feeling maybe that I'm having a crummy day and that's okay but relishing in Lou or someone else that's having a beautiful day and having that both lift you up out of it but also just sort of this appreciation that we're in this. Yeah, I don’t how to articulate that either.**Interviewer:** That's quite beautiful love, looks like when you love somebody that’s --. [00:38:00:06] Something you said, Leah, maybe I think which is what we all do, is that four of you have your antenna up for what Matt and Myra need. Did you let yourself pay attention to what you yourself needed? Did you give yourself, I mean, this is something we all wrestle with, taking care of yourself. Did you let yourself think about taking care of yourself?**Leah:** I think teaching is good. I think taking care of ourselves was less of a priority, which feels appropriate given everything and also I think we all know that we need to, like, also need to prioritize our health and wellbeing. I [00:39:00:05] completely agree with what Jacob was saying earlier about we learned so much from Myra and Matt and they've made the study of grief and the grieving process such an active part of their life, as he said, through CPN and you and Charlie and with Dr. Joe, and they've been so generous in sharing that with us. And I feel even though a lot of it is in the context of them sharing it and how they're moving through their grief it's, of course, really helpful and therapeutic for us to learn and hear about that from them, and so I think I've been able through that to kind of learning through them doing the work that way, but I think in general our priority has been them and --**Jacob:** Yeah, I think we – I know sometimes when we’re falling asleep [00:40:00:03] we’ll try and process how we're feeling and the reality is sometimes we've just had to remind ourselves that we are making conscious decisions and choices to be support and that then naturally you don't prioritize yourself there because you're in a support role, and almost naming that and knowing that is has been as helpful to recognize when we are in a moment of, or whatever that moment is, whatever time period that moment is that we are in a support role and that if that's what we want to do then we're going to do that and we're going to accept all that comes along with it. And I think there are definitely times when the spidey-sense goes up and you say, well, we're not prioritizing ourselves, we're not prioritizing each other, we're not prioritizing what's best for Leah and Mike, or our folks [00:41:00:04] and yet I think consciously we've chosen to support most of the time. |
| 7 | TC: 41:37Title: *Giving is living.* *This is a choice we’re making.*The aunt of a little girl, Havi, who died from Tay-Sachs, talks about how loving on Havi and her parents was a gift she gave herself; and on how she is finding ways to keep loving and giving following Havi's death. https://youtu.be/X4MJsqh7cPY**Erin:** We've all been reading or rereading Tuesdays with Morrie and there's a quote, I think that Morrie says where giving is living, and I think we're all just naturally wired that way. And when [00:42:00:05] Hav was physically with us giving to her, giving to My and Matt, like, was taking care of ourselves, that's what felt really good like a hug or a laugh from Hav could keep you going for at least a week. And it's harder now that she isn’t physically here with us and I think we're all trying to learn and find ways to connect with her and find those same #[42:38], like a gust of wind or something purple as purple sunset and that's what we need, it doesn't last as long but that's sort of the jolt. And I think for us there sure are times when I think we all have felt really overwhelmed [00:43:00:05] and it's a lot, but to Jacob’s point it also feels really good to know that this is all a choice that we're making, and I don't think any of us would have changed any of it. |
| 8 | TC: 44:40Title: *Sibling boundaries: Close as a unit but also tending to our respective marriages.*The aunts and uncles of a little girl, Havi, who moved to be close to the family and lived together following her diagnosis with Tay-Sachs, talk about how they made it work. Boundaries, finding FULLness, tending their respective marriages. https://youtu.be/16cGPq5Z0Ys**Mike:** When you live under the same roof boundaries very naturally disappear [00:45:00:07]. But I think one of the things I love most and feel so fortunate about being -- having this group as my family is I don't think boundaries exist in the most wonderful way. I mean it's -- I just -- everyone is very open and honest and so supportive in the most genuine way you can imagine and in that environment we're all -- I view these everyone as my siblings, we call ourselves siblings and I want to know everything about what's going on in everyone's life and at a real level, and I think we all have that, and it's -- I think also from people who are outside of our pod, it's a little weird maybe at times because they're like, wow, you're very close and we [00:46:00:05] kid that our neighbors here seeing two different couples living under the same roof have kind of questioned what's the deal, but I think it's so beautiful and every day you kind of relish in it and – but to others I think they would definitely say there are not boundaries and does that get weird, but I think it's great, I really think it’s great.**Leah:** So how do you start off the morning?**Erin:** Running with Mike, he’s in his boxers, he’s heading to brush his teeth, I can tell it's a good night of sleep with his hair sticking out. But I think we've all been mindful or aware of our relationships to both as a unit and as the sibs, [00:47:00:04] but then also our individual relationships Jacob as my partner and we just had to put more energy into the -- we're going to go on a date tonight. Mike and Leah went on a date last night and we want pictures the entire time and we stand outside the restaurant sometimes. But I think one of the things that is so clearly important, and if I were to give any type of advice, I don't feel in a position to do that, but if I were I would say putting in that effort and that energy and being mindful of keeping caring for and giving attention to that relationship is at times it feels really hard or harder than maybe [00:48:00:05] during other periods of time but it is so important. I think we all, as of right now, after the hardest two years of our lives in our individual relationships are better than ever and stronger than ever and I think a lot of that is because we have been mindful of caring for those things.**Jacob:** I'm thinking Matt has decided that he doesn't like the word happy and has sort of replaced that with full, and I'm thinking about the question about boundaries in the context of fullness and I think our lives have just gotten a lot more full. And at times to Mike's point, others can perceive the fullness of six adults or, if our folks are here, 10 adults and with Kai around the numbers grow. What are these guys [00:49:00:05] all doing as a pod? But the fullness is real and felt and then I will say though there's a transition when Hav was physically with us and now that she's not physically with us and trying to understand where to get that fullness and also then what now feel like creeping new boundaries around how we spend our time together, who we spend our time with, what are we supposed to be, all that stuff starts to creep in differently. And so, that's something I think we've been increasingly attentive to recently. |
| 9 | TC: 52:20Title: *Showing emotions with each other and Havi’s parents*The Aunts and Uncles of a little girl with infantile Tay-Sachs -- who moved to be near and support the family -- talk about wanting to protect the parents from their own sadness; and how the mom encouraged them to share and show their feelings - to grieve together, collectively. The balance between sharing and protecting. Communication is key. https://youtu.be/raJ4\_7GVqdY**Leah:** I think it feels instinctual to want to protect Myra and Matt and make sure that we're not asking them to take care of us or putting them in a position to make them feel like they have to tell us it's okay because it's not okay and also we don't -- we just -- we don't want to put anything extra on them, so it feels instinctual to protect them from I’ll say from my especially hard moments, and Myra said that she doesn't [00:00:00:13] want that to be the case, she wants to see our feelings and have us be real and bring them into our grief as well, that it feels good for her to be able to kind of move through that with us. And so, I think it's a balance and I think it's kind of situation by situation. I think because we've lived together for so long we're pretty good at reading where they are and what their capacity is at any moment. And so, sometimes it feels like it's therapeutic to bring them into my feelings and other times it feels like a burden and it's easy to find support elsewhere.**Jacob:** My [00:54:00:09] and Matt said something early on post-diagnosis that they would soon be treated like aliens by everyone and that sort of stuck with me as something that I never -- I was always, will always, will forever be Myra’s brother and I'll always be Matt’s brother-in-law as long as My has Matt. Now that we're clear on that, I never ever want it to be anything but myself with My or Matt, obviously, but – and they modeled really good communication, they're very good communicators and ironically Hav was an amazing communicator, she never talked, she was an amazing communicator. So they clearly gave that to Hav. And so, it can't be taken for granted but it was definitely in place [00:55:00:06] that there's a lot of communication and there has to be so that you have a baseline understanding of where each other are. I will say for me when I cried I typically would cry in the shower in the morning not because I was afraid to cry elsewhere but for some reason that was just my space and that's when I would cry. There were other moments but there was something about it where I -- it wasn't that I was afraid to show either of them how I was feeling but I don't know. You just sort of separate those worlds, I guess. |
| 10 | TC: 57:10Title: *Some support tips for other aunts and uncles*<https://youtu.be/PgpSxVGe0XY>Aunts and Uncles of a little girl with infantile Tay-Sachs -- who moved to be near the family -- share some ways they helped the parents: providing respite for sleep, celebrating events and hosting micro-beautiful moments and meals, finding equipment to keep her comfortable. Equipment tips to help with oral feeding: [Dr. Brown's Baby's First Straw Cup](https://www.amazon.com/Dr-Browns-Critters-Orange-Single/dp/B0741MGL99/ref%3Ddp_prsubs_1?pd_rd_i=B0741MGL99&psc=1) and [Sassy Baby Food Nurser](https://www.amazon.com/Sassy-Baby-Food-Nurser-Silicone/dp/B00XF7CA9O/ref%3Dsr_1_1?dchild=1&keywords=sassy+baby+food+nurser&qid=1634516846&s=baby-products&sr=1-1) and [Ark's Z-Vibe Travel Kit with Spoons](https://www.amazon.com/ARKs-Z-Vibe-Travel-Spoons-Lavender/dp/B005FMLNVS) [Arden Hill](https://speechandfeeding.org/) - really helpful for feeding therapy and food recommendations as it got harder for Hav to swallow. [Peaceful Passage at Home](https://peacefulpassageathome.com/) - Peg is an incredible resource for in-home funerals and end-of-life support. **Leah:** Some practical things, I think there were a lot of stretches where sleep was an issue. Early on with Kai, when Kaya was born and also Havi went through. As he said earlier, she was never a good sleeper but I think trying to make sure that Myra and Matt got some good sleep, we would have Kaya sleep at our house some nights or we would stay in with Hav while she was napping overnight otherwise she would kind of startle herself awake and she needed somebody there and so, if Havi could get a good stretch of sleep [00:58:00:09] and Myra and Matt could nap or kind of helping them maximize their sleep and taking some of the load off there is one thing that comes to mind.**Erin:** We call this place so lovingly the sleep farm because we get Kai for stretches at a time and just trying to make sure they sleep. But I think some of the other things that we did was just help in the celebration of Hav and Hav’s life and Shabirthdays immediately come to mind and that was every Friday where we celebrated what would be I guess a year of Hav, but once a week and it became this really amazing tradition that we've carried on through today and we got 57 of them with Hav here physically with us and I don't know how many we're up to [00:59:00:15] now. But I think for us one of the things that was, I think, really helpful was just putting a lot of love and care into those celebrations and it was, you know, Lou and I making some of Hav’s favorite food and blueberry pancakes and cheesy eggs for dinner and it was sending out beautiful lavender flowers that were the essence of Hav. It was just a lot of the celebration and putting effort and energy into that, which I think like gave them, gave My and Matt a boost, and Hav was a total diva and loved it, so that also felt really good.**Leah:** That’s true.**Mike:** We're also over there with them every day. So I mean, it's kind of hard to count I feel the practical levels when you're just [01:00:00:06] with someone, it's just on a day-to-day basis. These two in particularly and Erin are just superheroes in my mind in terms of what they did and continue to do. But when you're just around somebody who help in any different number of ways on a daily basis and I think all of it was practical in some way, but one thing that stands out to me is Leah got Hav these cups that she was with these straws that she was able to use to feed in a very impactful way. So there was some and some of that came from Leah's training in speech language pathology and feeding and using that to help Hav and help My and Matt with feeding I think was very impactful.**Jacob:** Yeah, [01:01:00:05], Mike, you took the words out of my mouth with superheroes for Leah and Erin and now we joke about it that these two are primary and we are secondary. But I think the primary designation is a result of all of the things that Leah and Erin did to make Hav’s life beautiful and also make her comfortable and same for My and Matt and in that way the amount of care and love and attention, anything you can imagine. And so, practical for these two is different than practical for the rest of the world, I will just say that, and it ranges from what seemed like basic things around adjusting pillows to make sure [01:02:00:08] that the angle is exactly right and then if it's a little off it's going to get adjusted no matter if a grandparent or whoever did it to making sure the spacing on the memorial program is perfect and the range of what is practical and what is feasible is a really -- it hits a nerve for me because I agree with Mike, these two are superheroes, so that’s to be said. |
| 11 | TC: 1:02:30Title: *Initiating support for and conversations about end-of-life*The aunt of a little girl with tay-sachs talks about approaching the mother and father about their wishes for end of life. "Saying we will do whatever you want, we'll talk about it when you're ready, we'll just listen to your needs and how we can help with those arrangements, and doing any of the logistical or understanding those processes behind the scenes." ​ <https://youtu.be/-C-s2fUbleQ>**Leah:** I think one of the things that was the hardest to navigate in terms of how can we be helpful was around when it became clear that Hav was really nearing end of life. I know, we kind of had conversations about should we initiate talking to Myra and Matt about how they want us to help with any end-of-life arrangements and service [01:03:00:07] or the funeral home, anything around end of life and after-death care. That felt the hardest which is – it felt unnatural because we all communicate so openly about everything but I remember a lot of conversations about when to approach them and how to approach them, and ultimately they came to us and said, when we're ready we're going to ask you guys to help us because we're not going to be able to handle it, but I think -- if I'm thinking in the context of how can this be helpful to other people I think getting language about how to approach that conversation and even just saying we will do whatever you want, and we'll talk about it when you're ready, and we'll just listen to your needs and how we can help with any of those arrangements and then kind of doing any of the logistical or understanding those processes as much as [01:04:00:15] you can behind the scenes unless they've expressed that they want to be a part -- the parents have expressed that they want to be a part of all of it.  |
| 12 | TC: 1:09:20Title: The Power of Ritual: “The ShaBirthday”Aunts and uncles of a little girl with Tay-Sachs, Havi, describes the origins of their family's "ShaBirthday" ritual which they celebrated every Friday of her life. Celebrating Shabbat and her birth, every Friday. It was a time to celebrate Havi intentionally and to let friends and family in. They had 57 ShaBirthdays during her lifetime and continued after her death to honor her life. The ritual helps keep her very present.https://youtu.be/G-EKurw6ODE**Leah:** So I think in the first couple of days after Hav was diagnosed Myra and Matt were driving back, either from an appointment or from talking with you and Charlie, and said that they wanted to celebrate Hav as much as they possibly could and that it wasn't fair that she was only going to have two birthdays and so they wanted to fit as many birthdays as they possibly could in her time here with physically. And so, they decided that every Friday we would do that and they called it the Shabirthday which was combining Shabbat, which falls on Friday, and birthdays, [01:10:00:08] obviously. And the reason that they chose Shabbat is because challah is the only thing that really ever motivated Hav to crawl. So Hav was amazing and strong and determined and somehow managed to crawl forward and usually or only it was in the presence of challah and so that was early on one of her most favorite foods and what motivated her to move forward. And so, Shabbats were really special and evoked Hav. And so, we had 57 Shabirthday celebrations with Hav physically with us. We celebrated on the first Friday after her diagnosis, we were already celebrating Shabirthdays.**Jacob:** And there were very musical family friends, the Paskins who [01:11:00:04] wrote a rendition that combined a blessing over the bread or the challah, hamotzi and happy birthday. And so this is a very musical rendition of what became the Shabirthday song and now we just do a traditional hamotzi because we sang the Paskin conversion of the prayer when Hav was physically with us, but --. Yeah, there was a lot of energy and creativity that came that had helped us celebration of birthdays.**Leah:** And the Shabirthday has sort of since transitioned into an intentional time to think about Havi in a very intentional way and to celebrate her in an intentional way. So, Erin mentioned that now we bring readings or thoughts, [01:12:00:05] observations, or song lyrics or anything that makes us really think about Hav and so it's a time that’s intentionally set aside to grieve her and celebrate her and honor her in a deeper way.**Erin:** It also has become -- it always has really been this way, but it's felt like a moment to let others in. We had a lot of people that would join us on Shabirthdays and it feel like My and Matt especially really leaned on family but also the people in their community, friends and that just were amazing and cooked and helped and did just some incredible things. But it gave us this opening to bring people into Hav in a way that [01:13:00:08] felt very Hav. And so, if you go back and you look at pictures of -- we took a picture every Shabirthday and if you look at pictures of 57, almost every single one there's a new face that now knows what it feels like to celebrate Hav and to be with her. Cut back to: 1:06:20**Erin:** And thank God that we didn't listen to that because that is the thing that we look forward to. Shabirthday is the thing we look forward to every week. I'm giddy on a Thursday thinking that tomorrow we get to wake up and talk about Shabirthday and what we're going to do for dinner, and we all try to bring beautiful words whether it's poems or just words that capture the essence of Hav, so now there's a little bit of research that goes on during the week. And yeah, I think what it's [01:07:00:05] done for me is that Hav is not a memory I have that I sometimes go back to and think about or access, but Hav is like part of us and part of what we do and how we are.**Jacob:** Yeah, Hav is so much the head of the table and I think at the head of the Shabirthday table when she had her little seat. I forget who got her the seat.**Leah:** She had that I think –**Jacob:** Then ultimately it was – **Erin:** I think it was Mary and Annie.**Jacob:** Mary and Annie got her the seat that actually she could sit in and it was comfortable, and she was a Shabirthday birthday queen and she loved it, and she loved things that tasted good. She loved beautiful things, she loved the presentation to be just right. |
| 13 | TC: 14:10Title: *Protecting the (grand)parents*The aunt and uncle of a little girl with infantile Tay-Sachs -- who moved to be near the family -- reflect on how their parents (the grandparents) showed up in so many selfless ways, including taking care of all their children and their grandchild. "They made it possible for us to take care of Myra and Matt. And they did it quietly too." https://youtu.be/RpRCdIKC9f0**Jacob:** Yeah. Our parents moved to Jamaica Plain from Philly and they moved three quarters of a mile away and rented a house that has become uniquely their house. They dropped everything but for my mom's dad, they also grandfather nabbed and brought him here as well, so our grandfather, Zaidi, we call him, is turning 101 this December and so they brought him from Philadelphia, and so the three of them moved [01:15:00:12]. And Le, you should share your own sort of feelings about our parents, but for me on the question of support and protectiveness, you know, this is why parents are different, I get it. My parents are amazing people and they have so much capacity to give and support and be parents and take care of, which is all the things that I can imagine My and Matt feeling with Hav, but despite the fact that my parents were taking care of 101-year-old and didn't have the flexibility, [01:16:00:04] didn't have the time, didn't have some of the things that we have, they took care of us, they took care of me. I felt like they were the ones who were asking the questions always about how are we doing, sort of helping us separate what's important to us, their children, in addition to their role as grandie and granddad for Hav and Kai and then as parents to My and Matt. And so, their move to Boston in Jamaica Plain, though I probably wouldn't have thought at the time, made a lot of what we were doing more on a daily basis for My and Matt possible and that's always been the dynamic with my parents. **Leah:** They did it all really [01:17:00:05] quietly too. They were so concerned about making sure that they were never overstepping or intruding. Dad sometimes would disregard that when he would show up at their house at 6 a.m. or your house at 6 a.m. after run. But, no, they were just so aware of protecting Myra and Matt’s space and helping how they can but being behind the scenes, and Mom would go over every afternoon when Tia, who helps watch Hav and Kai, she would leave and mom would come tag her out every single afternoon. And yeah, I echo everything that you said, they're incredibly supportive and selfless and wonderful people and carried us all and continue to carry us all through this nightmare.// |
| 14 | TC: 1:22:15Title: *Bereavement: Leaving the pod*The aunts and uncles of a little girl, Havi, who moved to be close to the family during her life, talk about finding their way following Havi's death. "Priorities have changed; coming to a reckoning with that while the real world rushes in is a struggle." They talk about their experience and how their togetherness will last forever. "We're figuring it out day by day." https://youtu.be/W7QH5dYXPScit is changing, it's confusing. Every day I think we have an internal struggle of what are we -- what are the next days, weeks, months going to be looking like and -- I mean, I don't want to have an easy way out here by saying it's too close but it kind of feels like that because we're very much in the middle of it. I don't think we fully processed our emotions about it. We feel like we are connected to Boston [01:23:00:03] in a way that neither of us – from Leah’s and my perspective I think ever anticipated. And the thought of transitioning back to Dallas is immensely difficult on a number of levels and within including because the pod is changing and we're no longer going to be within a five minute walk of everyone, and something that Jacob said at the very beginning, priorities have changed over the last year and a half. And so, kind of coming to a reckoning with that while trying to deal with this real-world kind of coming back to us in our own personal lives is a struggle.**Leah:** Yeah, I agree. [01:24:00:14] I'm in denial that we're going back and it's terrifying and awful. But I love you and I’m excited to be in Dallas alone. It's so overwhelming to think about leaving and painful. But I think what has become clear is that ultimately we've always known that family is our priority but this has shown us that we really do -- physical space matters and that we want to be in the same space. And I think as each of us kind of prepares to start to transition back to some of the things that we have left to come to Boston that feels pretty temporary and kind of a bridge until we ultimately all settle back [01:25:00:08] into the same place.**Erin:** This is all where we go from here, what we do from here, there's just this tension I feel between -- unless you've really lived through this you don't really know that, you're actually in this for life. I think from the outside looking in you might think like this is the end of a chapter or something and now you turn the page, that's not what it's like. This will be with us, Hav will be with us, we’ll constantly be thinking about how we and where we find Hav and how and where we find each other, and then there's like sort of the tension of feeling that with also new things [01:26:00:06] and new places and new experiences and wanting – I think the natural feeling is to think that that's like you're moving on or something. And so, when you don't feel that way but that's coming for you it's sort of this confusing -- and this is all happening right now for us but it's just sort of this tricky thing to process. And I think we're just sort of figuring that out day by day into what Lou said, there's some sense -- at least it gives me some sense of calm or peace to know that for right now it's okay that we will go do something new or we will go maybe not live under the same roof, it's probably good for all of us, but to know that what we're all after is to be together, [01:27:00:14] and to know that that sort of our new North Star or something. **Jacob:** Yeah, I agree with what everyone said. The one thing I'll say is something I said at Hav’s memorial, which is when she and I were sitting together on this dock in Tomales Bay, we're listening to a podcast and the poet, Pico Iyer, talked about the joyful participation in a world full of sorrow, and I think in part when you ask about what has changed look like, what does the next chapter look like, how does it mean to sort of physically be in different places more often I think of two things. One, I think that you're sort of asking, well, will you continue to do things that are meaningful, the most meaningful, and the answer to that is, yes. And then the second part that I think was, should we joyfully participate and try to joyfully participate and I think Hav would want that and I think [01:28:00:06] we owe that to each other. In the next sort of phase of grief and a phase of being together in a pod and remembering Hav’s life in a different way and to be determined. |
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