APPENDIX A

Life after invasive meningococcal disease: Insights from survivors and their caregivers

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Appendix A. Long-term phase: Quotes from survivor and caregiver interviews

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Sequelae post-IMD recovery

Physical sequelae

Physical sequelae	Supporting quotes
Reported by survivors	
Difficulty walking/issues with mobility	• ***Walking is the most difficult*** *because of the wounds on the bottom of my feet. The scarring and such, it starts hurting after a while. Just finding a pair of shoes that are comfortable.* • *Well, because I lost all of my toes, I* ***cannot walk or even stand*** *without wearing carbon fiber leg braces. First of all, every morning when I wake up, I got to put on those leg braces, and I got to wear them all day. So that's a very different experience. And I can walk. Sometimes I have pain in my feet, so that's a limiting factor.* • *I* ***cannot run. I can't change directions quickly*** *like you need to do to play sports. I can't jump. I cannot get up and down quickly in terms of getting up from a chair or getting down on the floor. All that process takes a little bit longer.* • *Yeah, I think it's also working my body so much. Because I'm basically standing on my stumps on these prosthetics, so my body's working 10 times as harder. And so it's like sometimes if* ***I move too fast, I can probably sprain a muscle*** *or I'll do it too fast or do it too hard. I try to do much of my stretching as possible to make sure I don't injure myself.*
Balance issues	• *I just walked into my kitchen right now and I could feel the second that floorboard goes up just a millimeter. I'm constantly feeling I'm really kind of like* ***destabilized*** *by these things. Even though I might not register it on a conscious level, it's getting registered constantly on an unconscious level. It's a lot.* • *But also I will* ***lose my balance*** *sometimes. And it's also due to not being in the best shape, but sometimes I'll lose my balance sometimes.* • *Like,* ***my balance****, what's left of my feet is not great. Maybe 60% of what it used to be, even with the braces on.*
Scarring	• *Well, I have a* ***ton of scarring*** *all over my…like pretty much every part of my body has scarring on it. I have issues with wounds forming, especially on my legs, because of…They're basically just covered in skin grafts. There's not a lot of muscle there. So, it's like skin graft on bone. That happens a lot, unfortunately. My hands get so dry that my skin breaks open.* • *I have a half of a right foot and* ***scarring*** *down my leg, and skin grafts on my stomach, my face, my nose, my forehead. I've had reconstructive surgery where they've taken donor spots all over my body. I have a half of a right foot and a partial left foot.*

Physical sequelae	Supporting quotes
	• *With the meningitis, all my skin has a scaly or snakeskin-type look to it because of **scarring or skin grafts** in the arms and the legs and on my face as well.*
Amputation	• *My first hospitalization, if I count XX and XX, that was 10-11 months. Since then, because of the kidney failure and I **lost both my legs and most of my fingers** and the skin grafts and everything, I've had many, many surgeries. Like I'm not even exaggerating, over 100 procedures.* • *I can tell you my surgeries started the day I got sick. They started to try to save my arms and legs, which they did, my extremities. I have **a half of a right foot** and scarring down my leg, and skin grafts on my stomach, my face, my nose, my forehead.* • *They **amputated all 10 of my fingers and they amputated both of my feet**. It was an extensive surgery and then physical therapy during the time.* • *Yeah, I'm a **quadruple amputee** now. All my fingers and both my legs.* • *The result was that I lost parts of my hands and feet…*
Fatigue	• *There's been a lot of days where I could have done things but I was just **so tired**. I couldn't **get out of bed or I couldn't leave the house**. I have regrets about that.* • *I'm **exhausted all the time**. Yes. I mean, I think trying to achieve goals, one of the hardest things I have to overcome is just how exhausted I am. I'm just exhausted. I'm exhausted mentally from the pain, and exhausted from the pain, but I mean I'm still an active mother like I said.* • *Nothing that I'm missing out on. I just **get tired more easily**. I have to take more breaks than the average person. Going for a walk could put me out of commission for the rest of the day. I get brain fatigue, just really easily.*
Reconstructive surgeries	• *I had a lot of plastic surgery when I was small, when I was young, a lot of **reconstructive surgery on my face and hands, and legs**. Because of the meningococcal, obviously I'm an amputee and my face was damaged pretty severely, my nose, my lips and so most of my memories of my childhood have to do with the hospital.* • *The parts that have been affected are nose and mouth surgeries or plastic surgery. Couple of those, **knee surgery**. A **Z-plasty** on my arm recently, was the most recent one. That was a*

Physical sequelae	Supporting quotes
	surgery on my arm *because there is a thing that would not let me extend my arm out fully.* • *The plastic surgery team a lot, because I had a…I needed a lot of* ***skin grafts and reconstructive surgery****.*
Reported by caregivers	
Amputations, reconstructive surgery/skin grafting	• *They cut a deeper web space so that he would be able to have a usable thumb on that side. He had* ***lost all the fingers*** *on his right side, except his right thumb. He had* ***lost half of each foot****. He had extensive* ***skin grafting****.*
Scarring	• *He came back in full splints and pressure garments for the* ***scarring****. Then he had a facemask as well that he used for facial scarring.*
Fatigue	• *He's able to do pretty much everything he wants to do as far as I know. He has like this labrum…hip labrum tear that kind of…I think he was glad not to be rowing anymore because that was exacerbating it. My understanding is he* ***needs more sleep now****. His dexterity is not what it was. For him to sleep is a huge deal. This is a kid who stopped taking naps before he was 2.*
Difficulty standing	• *At his age, he doesn't know everything fully or anything. But he's done really good. Meningitis is not going to get the best of him. I know that. I mean, it's definitely interrupted how his life would have went. We always say* ***you can't necessarily physically stand up straight,*** *but he's a stand-up guy.*
Difficulty walking	• *He needed help with everything. He was so weak, he* ***couldn't walk around by himself.*** *He couldn't go to the bathroom by himself, and we're talking like 10 feet away from his bed is where the bathroom is. He just was still very, very sick and weak.*

Abbreviations: XX, personal identifiable information redacted from interview transcripts.

Neurological sequelae

Neurological sequelae	**Supporting quotes**
Reported by survivors	
Numbness/ loss of sensation	• *Sure. Now—and I think this is just from me testing it because I'm crazy—if I walk on something hot or* ***if I walk on something cold, it feels the same or it doesn't feel anything at all.*** *I walked on a nail and didn't really know that it went into my foot until too late, [laughter] so just a little bit of loss in sensation in my feet.* • *I have* ***nerve damage in what's left in my feet, yes, so my feet, my lower legs have some loss of sensation****. Yeah. That's true.* • *After amputation, it's probably because of the numbing, not numbing gas, but the gas that they used to make me go to sleep or whatever. I kind of like feel my foot there, or my leg there after the surgery.* • *The neurogenic bladder, I have several areas of my body where I have* ***no sensation, nerve wise****. Certain parts of my body where I can't feel, which would also be related to that. And that's, I guess probably…*
Nerve pain	• *The pain goes from my feet up to my legs. Then, sometimes on my arms, too. They diagnosed it as* ***peripheral neuropathy****.*
Motor problems	• *Yeah, so I think that was referring to kind of my* ***fine motor skills*** *that kind of didn't fully recover. So my handwriting I would say got worse, and I struggle with very fine motor things like if I try to thread a needle or very precise movements like that. My hands are much more shaky, and I can't really do that as effectively as I used to be able to.*
Sensitivity to light	• *I just feel this…it's hard to explain. This feeling in my gut* ***when the lights are too bright. I just feel sick.***
Hearing loss	• *I have…in my right ear, I have roughly, let's say, two-thirds of my hearing. In my* ***left ear, I have about one-third****. But it wasn't…I could never hold up the phone to my left ear. Ever. It would have been very distorted.*
Vision problems	• *The meningitis caused* ***damage to my optic nerves****. As a result of meningitis, I'm* ***totally blind in my right eye****, and I have clinically about 20/300 vision acuity in my left eye, which is 20/300. It's kind of hard to describe. I call myself*

Neurological sequelae	Supporting quotes
	ambiguously blind, because technically I am. Sight is something that happens in a spectrum. It's not all or nothing. My sight is ***not correctable by lenses****. I can't correct it.*
Confusion/disorientation	• *Yes. Yeah. I do, I would say infrequently kind of feel like I'm more susceptible to becoming…what's the word…****disoriented*** *than, I would say, my peers are or that I would be otherwise.* • *If I'm in class and something gets mentioned that maybe reminds me of a specific thing that I dealt with then, I kind of feel like I'm* ***floating a little bit****, and I'm not able to fully pay attention to what the professor is saying.*
Seizures	• *I have* ***epilepsy*** *as well. Doctors are unclear if it's the meningitis or brain surgery that caused that or if I've just always had epilepsy. I've had a few seizures in my sleep, at least I feel like they're seizures. Kind of a sleep paralysis episode.*
Brain fog	• *I have* ***brain fog****, but that's because it's a consequence of losing my kidneys from the disease.*

Systemic sequelae

Systemic sequelae	Supporting quotes
Reported by survivors	
Secondary infections/comorbidities	• *No. What I do is I prevent them to the best of my ability. If I get one, I have to go to a **wound clinic**. I usually have to go there every week until it's healed. Yeah. I have gotten infections. I have been in the hospital and had to receive like IV antibiotics and just be there for a while, which is always…* • *I wouldn't say that. But I did…**my vulnerability to viruses**, I think, potentially had been lowered. I had a really bad case of chickenpox. I've had COVID 3 times. Again, I don't know if they're correlated but I'm curious about my immune functioning.* • *I asked them if it was, but they said it was a possibility that it (systemic lupus) **may have been triggered by** my…Yes. Yes, it was a trigger. But they're not really sure.* • *No, no, no. Just being **medically fragile and getting sick so easily**.* • *I get sick if I travel. I'm supposed to go on a train to see my mom and my sister tomorrow and I just don't even think I'll be…my legs can handle a long day with my prosthetics on. But also, chances are, after I get back from flying or…I get sick.*
Musculoskeletal pain	• *As I said, muscular pain. I believe I have **arthritis in my legs and arms** already. Back pain, and actually mentioning medications, as an adult I very much…I limit any kind of I'd say real pain medication like any kind of narcotic pain medication like…what do you call it?*
Kidney problems	• *Renal because my **kidneys failed** and I was on dialysis at that point.* • *Yeah, I went in on the 24th. Then I believe it's the 25th that I had multiple organ failure that included several cardiac arrests. I don't know if they were all that same day. I had **kidney failure**, which was on the 25th. My kidney transplant was exactly 1 year later, on the 25th.*
Heart problems	• *Yeah, I went in on the 24th. Then I believe it's the 25th that I had multiple organ failure that included **several cardiac arrests**.*
Respiratory problems	• *My nose, it looks pretty good now, but my nose, inside my nose where they had reconstructed my nose my **breathing passages** aren't the greatest.*

Systemic sequelae	Supporting quotes
	• *Then I also had **respiratory failure** so I was 'trached'.*
Bladder issues	• *And the nerve between, I guess between my spine or my brain and between that and the **bladder**, that releases the bladder for urination was disconnected as well or damaged. Since I've been in the hospital, I've been using an intermittent catheter for urination about 4 times a day since then. That condition again, it's stable. It hasn't changed in any plus or minus, but that also was affected.*
Reported by caregivers	
Secondary infections/comorbidities	• *Because he did a limb lengthening surgery where they placed an internal rod and we did try to lengthen the **leg before amputation**. It got infected. So he spent about 12 weeks bedridden on PICC line antibiotics that I administered. He spent 6 days in the ICU because of **staph A osteomyelitis**. Those 12 weeks being on high-dosage pain medication and ending up having an infection, just all this stuff, you could tell it wasn't the same kid we went in before that surgery, after 12 weeks*.
Musculoskeletal/joint pain	• *He has like this labrum…hip **labrum tear** that kind of…I think he was glad not to be rowing anymore because that was exacerbating it.*
Heart problems	• *His **heart rate would shoot up**. He'd have to go sit down and rest before he could do anything else. That was terrifying. Because he had had multiple organ failure, including his heart, so that was really scary.*

Abbreviations: COVID, coronavirus disease; ICU, Intensive Care Unit; IV, intravenous; PICC, Peripherally Inserted Central Catheter.

Long-term impacts of IMD on survivors

Long-term physical impacts on survivors

Physical impacts	Supporting quotes
Reported by survivors	
Prosthetics/assistive devices (wheelchairs, walker, crutches, hearing aid)	• *But other than that, I'm putting my **prosthetics on** because I do wear prosthetics. So that's a process in itself to make sure that I put my pants on over my prosthetics and make sure they fit. And then I put my liners in to make sure that they're aligned properly.* • *Yeah, so that's kind of the big one. I do have **prosthetic legs**. And I have these calluses that kind of build on the end of your stump from them. Sometimes they get really dry and they break and then you can't put your prosthetics on. I'll be stuck in my wheelchair and my wheelchair…I don't have any fingers, so I have an electric wheelchair that's really at home.* • *Well, because I lost all of my toes, I cannot walk or even stand without wearing carbon fiber **leg braces**. First of all, every morning when I wake up, I got to put on those leg braces, and I got to wear them all day. So that's a very different experience.*
Headaches	• *I'm **very migraine prone**, which I also wonder about being connected to meningitis. Because I get headaches very…I basically **have a headache every single** day. It's just a question of is it a migraine today or a headache. I know that has to be related to having meningitis.*
Sleep disturbances	• *I do have…From my PTSD, I do have **nightmares**. That **affects my sleep** quality though a lot.* • *I think, you know what, I actually think that I have…I take **Aleve or Motrin before I go to bed with Ambien**, and I also…I think I have…I have like a **sleep anxiety**, and I think that actually roots from being a kid and staying in the hospital. I **wake up in the middle of the night in a worry state**.* • *When I go late at night, I'm less…that can affect my 2 weeks in advance, that I can't get my **sleep schedule** readjusted. So I have to avoid that. But also I had something just a minute ago. Just a second... I've had a few seizures in my sleep, at least I feel like they're seizures. Kind of a **sleep paralysis** episode. Those also cause me to be fatigued and not be able to readjust my sleep schedule.*

Physical impacts	Supporting quotes
Napping/needing to rest during the day	• *Yes, I work for myself. So I build in breaks into my schedule. Because when I didn't have that, the last time I worked for an employer, I would have to shut my door and take a quick* ***nap every single day*** *basically, in the middle of the day. Because it was so chaotic and so taxing on my brain. When I tell you…It could have been a 5-minute nap. I basically would…I would shut my eyes and I would immediately start dreaming. Then I would wake up and I would feel so refreshed.* • *Recently, I've been doing well, but a couple of years ago and last year, the sleeping, I wasn't doing well because I was kind of in…I would be a night owl, I guess, and just try to be up during the nighttime and hang out and play on my Xbox or whatever. During the daytime, I would* ***just sleep*** *and not do much.*
Falling	• *But at the same time, I almost fall.* ***I almost fall a lot right now****. I have fallen and hurt myself. Like the other day, I was transferring to the shower chair from my wheelchair and I got in the shower chair and was fine. Then I slipped and just bashed up my leg. That stuff happens to me a lot. One time I fell out of my wheelchair and I almost broke my tailbone and I couldn't sit for like 2 weeks. Just randomness happens.* • *Yeah. I mean, if I'm not wearing my leg braces, the* ***risk of falling is severe****. So if I'm trying to take a shower without a shower bench that I can sit on, there's a very* ***strong chance of falling****. If I have the leg braces on, it's greatly reduced, but it's still better chance of falling than before all this happened. Like, my balance, what's left of my feet is not great. Maybe 60% of what it used to be, even with the braces on.*
Injuries	• *It's mostly my bones, because of all the medication I've taken over the years, especially for the transplant. I just had a* ***bone density scan and they're very weak,*** *basically. In the past, I've cracked a vertebrae, in 2002, right after my transplant. Then I* ***fell on my arm and broke both bones clean****. I've had some issues with my bones where they're weak and they break easily.* • *Oh, it'll usually be like I'll get a muscle sprain or like* ***usually muscle sprains or muscle injuries.*** *But other than that, it's just mostly muscle sprains. I think that's me due to the lack of stretching.*
Reported by caregivers	
Physical impacts	• *They fitted him with…[a] prosthetic left hand. It sat in a drawer because he said, "It's not worth it. I lose the sensation that I have when I just use my hand." You have to be so careful when*

Physical impacts	Supporting quotes
	you grasp and when you unclasp it, that you don't drop something or crush it. So he very quickly decided he wasn't going to use that. Now those kind of ***prosthetics*** *are much more intuitive. But he's just…he just says to himself and us, "I've learned how to do things my way, so I don't really need that."*

Abbreviations: PTSD, post-traumatic stress disorder.

Long-term cognitive impacts on survivors

Cognitive impacts	Supporting quotes
Reported by survivors	
Memory issues	• *It's kind of like I forget things that just happened, like **short-term memory lapses**. I'm in the car and I'm driving and I **forget** where I'm going. Stuff like that.* • *It's just, I can't grasp it. I can't hold onto it. That stuff's been very stressful. I'm **forgetting** things that people have been asking me or telling me, which doesn't usually happen to me.* • *I mean, every day it comes back and either I or someone else mentions it. I guess that's what has caused me to think about it so much. I'm constantly reminded. Even through the pains that I have or the effects, **thinking about my memory** and being sad that I don't have the same joy about a situation because I don't remember it.*
Attention deficits/problems	• *Sometimes, especially in the morning, my **brain is very foggy** from dialysis.* • *Yeah, I'm kind of like **slow and daydreamy**. Like I said, I have ADHD. I have the **inattentive type**. I'm kind of sluggish. I need a lot of breaks…I can only meet with 6 clients a day, which is actually a lot. But I'm a hard worker. I think overall I'd be seeing like 9.* • *But once I have one of these, it's like my complete…the entire day is ruined because I can't **focus** on anything. I feel like I'm watching everything in third person, like it's an out-of-body experience. Usually these seizures come in groups. I don't have 1. I'll have 15 during the day. They just keep happening and I can never focus. I've had to step out of several classes. One day in high school, we had a test and I asked if I could make it up later. Of course, when you say "seizure", everybody gives you what you want.*
Speech problems	• *My **speech is not impeccable**. It's impressive for someone with the level of loss that I have. But it could be better.* • *I **couldn't talk**. I had to do therapy on my facial muscles to make words.* • *It's probably because I can't pronounce words correctly with the top teeth mostly. Some words are harder to say without those top or top front teeth, however you would describe it or how I would describe it.*

Cognitive impacts	Supporting quotes
Learning difficulties	• *I had to **relearn how to learn**. I was, I think a visual learner. I would look at the board or do things in class, and that wasn't going to work anymore. So I had to go through a lot of **adaption**, adaptation, and just kind of **retraining myself** to be more of an audible learner than a visual learner. So that took some time, and there was a lot of anxiety. I do recall initially in the first maybe 6 to 12 months of being back in school just feeling overwhelmed with the impact of all of that, just day-to-day.* • *Then in middle **school it was really, really difficult** because obvious middle school's rough for everybody.…I mean, it got to the point where I wish now that, you know, I had one semester to go. I was just emotionally drained. I had the surgery on my face, and I just couldn't. I think mentally I just couldn't take it anymore. I needed to take a break, and then life just kind of happened after that. I think that I remember some of the classes I had taken I couldn't walk to, and my teachers would try to give me a break and say, hey, you know, and I think at the time I still didn't want to be treated any differently.* • *So that's what mostly was happening. Most of my friends were not there because I was far enough away from school that they were there occasionally, but not regularly. I was kind of on my own basically **just working day after day on rehabilitating my body muscularly, neurologically, physically, and then working on adaptive equipment** that I would need to get back to college.*
Communication problems	• *I was half in a school for the deaf and half in mainstream…in regular school. Then I had **a sign language interpreter** from grades like…first grade until at least seventh or eighth grade.* • *Because anytime anybody loses a sense, then there's endless amount of things that that can impact. You mentioned work. I mean, I use **adaptive equipment for communicating**. I do have some **limited vision**, so I am able to see some things. But 80% of things, I can't see, I don't see. In my work, I use adaptive software and other adaptive tools to help me read and communicate. Technology has been good for that in the last many years. So that's improving for people with probably any disability, but particularly for me for sight loss.* • *I did a lot of things. I recuperated a lot of things and did a lot of therapy and training and computer stuff. I **tried to learn braille**. I was not able to learn braille.*
Reported by caregivers	
Cognitive impacts	• *Oh, I still worry about him. Yeah. He went back to rowing. He is obviously cognitively back. It was touch and go for a while. We had him evaluated because he **couldn't remember** anything.*

Cognitive impacts	Supporting quotes
	*He **couldn't read** a page and remember what he'd just read. Where he had had a photographic memory before that. It was scary every single day, wondering how and if he would really recover. Yeah, I still worry about him all the time.*

Abbreviations: ADHD; attention deficit hyperactivity disorder.

Long-term emotional impacts on survivors

Emotional impacts	Supporting quotes
Reported by survivors	
Worrying	• *Just being able to go out for 1 day and not have to **think about** when my legs are going to start hurting, when I'm going to need my wheelchair, if I have my handicap placard. You know what I mean? Just 1 day. That's all I really want. That's all I want.*
Fear	• *Yeah, mostly, I'm just **scared and stressed out** because I don't know. I'm forgetting something.*
Self-perception (mental) impacts	• *Definitely, I was a child and life was a lot more simple back then. I just went to school and played and that was it. After, a lot changed. I went through my teenage years which were **very difficult to be a young girl with a physically different body**.* • *I mean, I've learned to just kind of tune out **any sort of stares or anything**. Yeah. I mean, initially I had concerns about how I would be perceived because of my amputations and my skin grafting. But after a few years, I got to a place where it just felt like I didn't want to be concerned about that because it's exhausting to live that way.* • *Body image, okay, fine. My diet is so restrictive that I don't weigh a ton these days. But I would say my **self-esteem permanently took a hit,** just being **insecure** about standing out so much as a kid, being hard of hearing. I've always just struggled a little bit with feeling self-conscious. I can mask it well. People would not know that I feel that way. But internally, I do.*
Feeling different from others	• *School setting, I **stood out** because I had hearing aids and I had a sign language interpreter. So that was really uncomfortable for me.* • *Yes, I sat in front. Normally in high school, you're seated by your last name. I was always the **anomaly that sat up front**.* • *Mostly just playing sports and hanging out with other people that didn't really know me much. They saw I **wasn't the most normal**, like how everyone is around here.*
Trauma/PTSD	• *I don't like to use the word "traumatizing," but…[laughs] The experience was **traumatizing, the whole experience. I have PTSD**.*

Emotional impacts	Supporting quotes
	• *I hate to say **post-traumatic stress**, but I definitely have it. I hate the smell of a hospital. I hate walking in a hospital. I don't want to deal with anything to do with a hospital or doctors if I can avoid it. That's why I'm so glad we can do tele…When I go to the doctor my doctor has told me like, hey, your blood pressure's high every time I go, and we don't know if sometimes it's because I'm just stressed out about being in the office…* • *Yeah. So as far as, I would say…It's sort of like a psychological thing where I just…The **memory of the experience is very painful**, and sometimes something will remind me of it and sort of that will become the only thing I can think about. And kind of can be distracting from other things that are going on.* • *Just because of **fear, of PTSD.** Of course, there was some of that. So I think I may…I mean it's obvious anyone who goes through a traumatic thing like a quadruple amputation, they're going to have PTSD and anxiety, depression, that sort of thing. Whether it's always as severe as certain moments.*
Anxiety	• *The **anxiety,** it's like when one's bad, one's okay. When my depression is bad, my anxiety could be okay. Sometimes it's both.* • *Yeah, I would say that I have a fair amount of **anxiety and specifically associated with this event.*** • *Yes, I think it's…I think…I don't know. I have **anxious moments and depressed moments.***

Emotional impacts	Supporting quotes
Shame/embarrassment	• *After, a lot changed. I went through my teenage years which were very difficult to be a young girl with a physically different body. Caused me a lot of **shame, embarrassment**. I used to hide my body constantly with long sleeves and pants throughout the year, like in the summer.* • *If it isn't for the stuff I was explaining earlier about how I was hiding my **body and so ashamed of my body**, it's also…Goodness, I'm losing it.* • *Yeah. During that acute time, I was feeling, I knew I had really **low self-esteem.** There was also lacking confidence now my body was different, living as a person with a disability.* • *I just always…I would hide my hands the whole time I was with a new person so they wouldn't see my hands. Just **very self-conscious** and afraid that people would see and be grossed out or afraid.* • *Overcoming physical difficulties as a child and having scarring, I mean, I had huge scars on my face when I was little, and really I don't have them anymore, but I had huge scars on my face and I had my nose was deformed, and I had like a weird half of a lip kind of a thing, and so I think that that was…Sometimes it took all I had as I got older to **not want to leave a room like to just hide away**.*
Sadness	• *Well, I **cry** about it on a regular basis.* • *I guess that's what has caused me to think about it so much. I'm constantly reminded. Even through the **pains that I have or the effects**, thinking about my memory and **being sad** that I don't have the same joy about a situation because I don't remember it. I feel left out.*
Depression	• *It's definitely the treatment. Most people who are on dialysis are **depressed,** which isn't surprising. I also **deal with depression, along with my PTSD and some anxiety**. I've been dealing with that since childhood. Yeah, depression does get to you, especially, like I said, it's isolating.* • *I've decided I started taking the **antidepressant** and all this serious, or all this whatever you want to call it, all this 2022 because I realized that I was just…It's just a lot. It's a lot to deal with every single day realizing that you have a disability, but there's not much you can do about it. There's nothing…* • *I don't know if I've been, I think I've been diagnosed with **situational depression**, so that's really impacted me. It's just a really lack of just being ready to get better. So I was really discouraged a lot during that time.*

Emotional impacts	Supporting quotes
Anger	• *Yes. Like I said, probably the first 10 years after I was sick, I was very **angry, depressed**. **Victim, living victim mentality**, which worsens my depression and anxiety and trauma. It's all wrapped in each other.*
Self-consciousness	• *Because up until that point, I was very **self-conscious**. I still never wore my hair up, but I felt more free to just kind of…I just felt more…less self-conscious. So that was a big deal.* • *My interactions with others, I know I get the stares. Like, "Oh, what happened to him?" Or like, "Oh, he's missing limbs." Or, "Oh, he's wearing prosthetics." I know I get that feeling. Especially when I walk out the door or go to the store or I meet my clients or I hang out with my friends.*
Loneliness/isolation	• *I get around my house with a wheelchair most of the time. I go out with a wheelchair. It's very isolating. I do have a lot of support and friends and a boyfriend. But even with that, it's **very isolating to be disabled**. Even when things aren't…some things aren't accessible still. That kind of ruins my options where I feel like I can go safely by myself.* • *I mean, until I was in my 30s my family and I had never met anyone that had been affected by meningitis. Had never met anyone that knew the word meningococcal. I never had met any other survivors. I'd never met any parents. I'd never met anybody, and it was a very, **very alienating lonely experience**, and I think that a lot of the survivors that I have met now still echo the same sentiment that they feel like it is very alienating.* • *I think there's a sense of **isolation** just from the fact that most of the people in my life have not experienced something like this. They've not had a catastrophic health event that changes their entire life and their capabilities, and so that does feel isolating sometimes.*

Emotional impacts	Supporting quotes
Annoyance/frustration	• *It honestly…I try to be a positive person and I'm working on shedding that anger from all this. But it does* ***annoy me a lot****. It gives me a lot of stress, especially when you have only a limited amount of time on your off days and they're filled with doctor's appointments.* • *There weren't any issues other than that, I was just* ***frustrated*** *to be there. Because it wasn't particularly where I wanted to be. It wasn't because I didn't get along with them. I just felt like I shouldn't be there, because I'm 20 years old I needed to be doing that thing. That was a part of it. But really, more so the stronger feeling that I had was just more determination. Essentially, it was my fuel to get out of there and get back where I wanted to be. The* ***frustration and the sort of angst*** *of being there was what fueled me to work really hard to do all the things I needed to do for them to be confident enough to let me back out into the wild, so to speak, and be on my own again.*
Behavioral impacts	• *So I think that that's been helpful for me, also to* ***manage behavioral health*** *and mental health stuff. I think that's really worked in my favor in being able to manage it. I don't see anyone now and it's been years since I took any mental health medication. Years and years since I've done any of that. Because I feel like I manage it pretty well.*
Feeling of unfairness	• *When this* ***first happened, in the first few years especially, when I was a teenager, I was in victim mode****, as I like to say. Saying things like, "Why did this happen to me? I'm a good person."*
Panic attacks	• *Yeah. So, I sometimes have* ***panic attacks*** *associated with it. And, even if it doesn't rise to that level, sometimes it's like just…If I'm in class and something gets mentioned that maybe reminds me of a specific thing that I dealt with then, I kind of feel like I'm floating a little bit, and I'm not able to fully pay attention to what the professor is saying.*
Emotionally drained	• *This is in my entire life. It's* ***emotionally draining*** *and also physically painful.*
Regrets	• *There's been a lot of days where I could have done things but I was just so tired. I couldn't get out of bed or I couldn't leave the house. I have regrets about that.*

Emotional impacts	Supporting quotes
Reported by caregivers	
Emotional impacts	• *At one point, the neurologist we were going to, because [survivor] was still having these leg pains and back pains, gave him a pamphlet about depression. And said, "Maybe you're just depressed." [survivor] said, "No, I am not. I'm* ***frustrated*** *and* ***angry*** *that I can't do what I want to do. And I'm a little* ***scared*** *that I still have all these pains and I don't know if that's normal." He did not want to go back to that doctor again because he* ***made him feel not heard****. There were a couple of other things too with other providers who just didn't…they seemed to have their minds made up about something and just didn't listen*.

Abbreviations: PTSD, post-traumatic stress disorder.

Coping mechanisms reported by survivors

Coping mechanisms	Supporting quotes
Reported by survivors	
Mindset	• *Then I had this colleague who had lost his wife. I had just met him months before I got sick. So I think maybe…Then after I got sick, I realized that there'd been people who don't even survive it. So my perspective…wasn't why me. I felt like, oh, thank God, I survived. At least I have an option. At least I have my life, even if it's not the same life. It's not as good. It just isn't. It's significantly diminished. But I'm still very much happy to be alive and cherish it.* • *It's just about learning coping skills. I'm still trying to learn coping skills and things that help me calm down and get out of the funk. Because that just keeps me isolated, which is a big problem of mine.*
Community	• *Yes. Yeah, with time and talking to people and learning things about the world, I feel a lot less angry. I don't ask myself why me anymore. It's more like what can I do with this to help other people. What can other people learn from this? That's helps me not focus on the anger.* • *I talk to other folks that are similar to me, quadruple amputees and medically fragile. I think some folks struggle more than others. I think maybe something that helps is I was involved…the type of work, the non-profit, was homelessness that I was involved and still am involved in. So I feel like maybe my perspective was helped a little bit with that, because I saw people that suffered so horribly.*
Spirituality	• *As years pass, the anger subsides and I'm becoming more spiritual and things like that to help me get through it. But there's still anger there.*
Physical activity	• *Yes. Well, I was mono-skiing for a while after I got sick. It's adaptive skiing. I haven't been able to do that. I'd love to get back to doing that because it's the only sport I've ever done that makes me feel free and athletic and capable.*
Living with prostheses	• *I mean, I pretty much design my own prosthetics for my shoes, and I just move it from shoe to shoe to shoe, and then, so all my boots have a certain one in it. My Peloton shoe I have a special…like the Peloton bike that you clip into I have made my own shoe out of different…*

Long-term social impacts on survivors

Social impacts	**Supporting quotes**
Reported by survivors	
Relationship with others	
General impact on social relationships	• *It was **challenging, I would say, socially, growing up. Still is.** Just kind of having to piece together…really kind of almost being **master of an orchestra**, taking in all the different parts of an orchestra. It's just everyday life. Really piecing together through body language and through just other pieces of information to kind of like fill in the gaps where you missed conversationally.* • *And then of course there's the **social elements** of that and I was one of one, nobody else had the meningitis. I **didn't have any friends** that used the catheter for urination. I didn't have any friends that were vision impaired or blind. So **socially, it was challenging** to kind of acclimate back into that world that I had come from that I was different. So mentally, I was all over the place. I did go to therapy for probably about 12 months, maybe 10 to 12 months. It wasn't quite a full year.*
Impact on romantic relationship	• *If I'm just looking at someone from across the bar or table and I'm reading their lips and one on one, I can totally understand people fine. I don't even have to tell them that I'm hard of hearing. Then the second we…Let's say third date, you cook together, right? Now you're not facing each other anymore. **That's when all the hard of hearing problems come up. Suddenly, I'm very disabled.** I think it's very confusing to even explain to people. People don't understand hearing loss.*
Relationship with family/siblings	• *I'm very close with my family, but I would not say that they are…They're supportive, but when it **comes to my hearing loss, they're not nearly as supportive** as I need them to be. My mom is very absentminded and has never been good at looking at me when she talks to me, which quite honestly is unacceptable. It's been 35 years since I lost my hearing. She still can't get it right.* • *That's been something that I've…we've always fought about. It's not like my siblings know sign language or anything. It's not like…I was at school using sign, but then I would go home and it wasn't really used. That was always frustrating or just something I didn't even become aware of until later. Like wait a second. **Why didn't my family support me more around that?** So they're very loving but I don't think that they really have known how to support me in the right ways, unfortunately.*

Social impacts	Supporting quotes
	• *Then when I got out of the hospital, I continued seeing my brother and my sister and my dad off and on, because he was struggling. **They were very supportive.** They didn't say anything about how I looked. That was a big deal for me. They just kind of wanted to do stuff that I could do and enjoy, which was a big help. Same with my adoptive parents and the doctors. They were all very kind. Basically what they told me is, "You can do anything." So that was very helpful for me at that time in my life.* • *My mom was very adamant that I would grow up, and learn, and do the things that all the rest of the kids could do. They said that I was not going to be able to walk, and that sort of thing, but I do walk. I think that many doctors think it's a miracle that I can use my legs and my foot, but **I believe that's attributed to my mom**, and my doctors, and my family being supportive, and the school.* • *I was very determined to do that, and **my parents were supportive** of that, and that was my main objective. So everything I did was with that in mind. I mean, it was a good experience. I did a lot of things. I recuperated a lot of things and did a lot of therapy and training and computer stuff. I tried to learn braille.*
Relationship with friends	• *Because the normal patterns that I had been used to, had basically stayed the same. I **had very good friends**. There probably were some that didn't want to adapt for me or change things for me, but most of them did. But even at those things, it still made me uneasy.* • *I have a **pretty close group of friends**. It had to do with the support group, being able to get through it successfully.*
Support from teachers/therapists/HCPs /others/support groups	• *I would say…Well, **all of these people worked as a team**, which I was really lucky to have. There was a lot of communication between my parents and teachers and the interpreters and the teacher of the deaf and the principal and whoever else. The **guidance counselors at school**, any school therapy I might have received. I had a lot of eyes on me. I was very fortunate to have that.* • *One doctor, my plastic surgeon who did my feet, he actually hired me, and he was one of the part-time jobs I attempted because we got along so well. He had me do the front desk thing. I wasn't well enough, so it didn't last long at all, but the **relationship between myself and the doctors and nurses was always, really, pretty good**.*

Social impacts	Supporting quotes
	• *I just **loved them**. Most of them have retired, just within the past 5 years. So my nephrologist retired during COVID. He was with me since 2009 and was a **big part of my survival**.* • *Yes. My story is interesting. I was actually adopted by my plastic surgery NP at XX because my mom passed away when I was in the hospital. I know, crazy. She took care of me, so I had her.* • *My parents have a pretty **good network of friends** through their church that was able to support them in finding places for them to stay. And in one case, for a couple of weeks, they were able to stay in a hotel. They funded some of it as well. But through donations and things, their friends were able to help them. Because those are things that the insurance companies weren't paying for.*
Recreational impacts	
Recreational impacts	• *But it's like **half living**, like living with a cloud over your head versus a rainbow. But I'd still prefer the rainy days, right?* • *But it's just about **managing life rather than living it to its fullest probably**, I think is the best way to describe it. I guess a lot of people.* • *I just don't do nearly as much. Like before I got sick, I would plan our…at my job, our managers and directors retreat. One year it was paintball, one year it was fishing. All these…bowling. There's so many things I can't do anymore. But do I do things…**do I go along and watch other people do stuff**? Yeah.* • *I just went on vacation with my twin sister. She helped me. But we went to Hawaii and I just…**there's so many things I couldn't do. I can't go on hikes. I can't do anything. I mean I can't do most things**. It just really decreases my level of enjoyment. Like I'm just watching them go in the water and taking pictures of them. But I can't…I don't have water legs. Most people can't afford that sort of thing.*
Activities with others	
Activities with others	• *So some of the ways that people might make it work, I can't do. Yeah, like I said, it's just…**I still do social stuff. But just not as much. I can't do a lot of items**. Yeah, I'm a social person so I still make some of it work. I just don't do nearly as much or can't do a lot of the options.*
Understand/regard from others	

Social impacts	Supporting quotes
Understanding	• *People don't really understand what you're going through. Sometimes they have high expectations about what you can do. Even though I'm young, sometimes there's things I can't do and I have to push to advocate for myself, which is very hard for me. That's been a thing with people expecting more. Yeah.* • *And my support team with my sister, my twin, who really helped set all that up. Then just my knowledge of it. So I've been able to navigate it pretty well. I think I've been fortunate. I don't think that that's the case for most people.*
Reported by caregivers	
Social impacts	• *Well, he went back to college finally in August of '18. Because other guys didn't want to live with him because they thought he was going to be contagious and make everybody else sick too, he didn't have anybody to live with. They put him into like an accommodating dormitory room, where he had his own private room, private bathroom, whole bit.*

Abbreviations: COVID, coronavirus disease; NP, nurse practitioner; XX, personal identifiable information redacted from interview transcripts.

Long-term daily activity impacts on survivors

Impacts on daily activities	**Supporting quotes**
Reported by survivors	
Functional activities	
Trouble moving around/going out	• *I feel like even the simplest things…I'm trying to think of a **trivial thing**. I live in the South and we use trailers a lot to hook down our ATVs. We use ratchet straps, right? I often go and work…use these ratchet straps. But it seems like every time I do, when they're much spaced apart, every time I go and try to do…try to use the straps and stuff, I have to **refigure it out. I don't remember how I did it the month before.*** • *Yeah, it does. When I went deaf in 2020, I…now **crossing the street is very dangerous.** I can't hear where sounds are coming from. I can't just look both ways. I have to look both ways 5 times before I cross. I lost a sense, in a way.* • *I'll be **stuck in my wheelchair** and my wheelchair…I don't have any fingers, so I have an electric wheelchair that's really at home. I don't travel with it. I can't get into an Uber or my friends' vehicles with it. I'm just kind of stuck at home until…Then even if…I could even just get a cut elsewhere on my leg, not even on the callused areas and then…So right now, I'm like in…I'm stuck in my chair.* • *I have a lot of things lined up to help me with different things. I get all my groceries delivered. Transportation, **I have to coordinate with friends and Uber** and shared rides.*
Problems due to prosthesis/catheters	• *No. I do live by myself now. I have a lot of friends that help me. Either I get rides everywhere or I do Uber. I tried to drive, but I struggled with it. One of my **prosthetics got caught between the brake** and the gas pedal when I was on the freeway.* • *I also carry equipment with me for that. I **carry catheters with me**. Oftentimes, I'll have some sort of bag or jacket. I like to wear jackets because they got more pockets in them and I can carry those types of things a little bit more discreetly.* • *I took my shoe off and posed for a photo at the Peloton London like the TV studios, and that was a really big move for me, and I've started to get where I will actually take my shoe off at the airport and show them and say, look, this is my foot. I can't take my shoes off to walk through. At the*

Impacts on daily activities	Supporting quotes
	doctor's office, sometimes I will get on the scale and be like I'm taking my shoes off, but it's going to take a minute.
Household chores/daily activities	• *I do like to…**Driving and house chores, I actually don't mind doing, but I just get fatigued very easily**. Sometimes I literally can't do it. That's tough. I'd say I can…I'm not at the level of a fully able-bodied person but I can do pretty much anything. I can do laundry. I can clean dishes. I can do whatever. It's just going to take longer and probably be more painful.* • *Because as a person that couldn't drive and as a person that was dealing with some emotional baggage with that, and then of course I had this catheter thing for urination, which nobody that I knew did, I needed to know more specifically like, "Where are we going to be?" Because I'm going to **try to figure out how I'm going to go to the bathroom, how I'm going to urinate**. And that just wasn't a consideration that anybody else had, because that would happen wherever it happens.* • *It was really hard. Just adjusting to living my daily life, it was just harder. It was just **harder to manage my daily life**.* • *Yeah. Just basic, **using the restroom, it's completely different than a person just walking up to the bathroom**. Now it's me using a wheelchair and rolling myself to the bathroom, transferring myself to use the toilet like that.*
Diet/eating-related impacts	• *I have had to **severely restrict my diet**, to take out anything that is remotely inflammatory so that I can keep it at bay. Because I can walk into your house and tell you exactly where the floorboards in your home are uneven. I am very acutely affected by anything that's not even or the subtlest changes. It's really noticeable. But if I have…if I **cut out gluten, dairy, eggs, natural flavors**, things that increase glutamate, it gets worse. In fact, when that happens, I almost get like drunk and slurring my words more.* • *Yeah, it's **very food sensitive**. I wonder about the permeability of my blood-brain barrier. I just worry about…I truly believe that meningitis must have thinned it somehow. Because I have to **eat such a clean diet**. All I eat is like vegetables and fruit and rice and chicken. Otherwise, I start feeling lightheaded or imbalanced or migraine or I start slurring or whatever.*

Impacts on daily activities	Supporting quotes
Self-care/grooming impacts	
Self-care	• *Yes. So for example, like in the morning when I get up ready to go to work, I use the restroom in the morning. So I would have to* ***transfer myself from off the bed to my wheelchair, roll to the bathroom, use the restroom****, and then when I'm done, get ready to take a shower. I'll grab the necessities and roll myself to the wheelchair. I mean, roll myself to the bathroom and take a shower. But I have to transfer myself from my bed to the tub with my shower chair. And just I finish showering, and then from there I have to* ***make sure that I don't fall from my shower chair to my regular wheelchair and then get ready****. I make sure that I don't make myself, especially going through doorways or anything like that, I want to make sure I don't bump through with my hands or anything like that.* • *Now I think it's more of* ***just the basics are such a struggle. Getting ready, showering, putting on prosthetics*** *if I can. Like today, I have issues with my legs. There's like a sore. So it's a different mindset altogether. Different, yeah, thought process and approach to the day.* • *It doesn't take too much time. It's probably an extra 5 minutes out of my day.* ***But it makes it very hard to get dressed, there's a certain kind of pants that are in style, that*** *are tighter or something. It's very hard for me to get dressed and change when I'm out in public.* ***Even taking my shoes off and putting them back on is very difficult****. I try to be aware of that and plan ahead so I'm not stuck in a situation where I can't get my legs off and I'm in pain or something. There's a lot of thinking ahead.*
Physical/high-intensity activities impacts	
Physical/high-intensity activities	• *I'd obviously* ***love to run but I can't****. I have dreams about running though. But it's not the same…..Yes. Well, I was mono-skiing for a while after I got sick. It's adaptive skiing. I haven't been able to do that.* • *For the most part. Hiking is something I* ***have no interest in because of my balance problems.*** *But interestingly, because I don't really…Because my balance nerves are so destroyed, I have the ability to spin around a lot and not get dizzy.* • *Some things I just can't do. Like hikes that I used to do. I know that there's some amputees that do stuff like that, but quad amputees and…I can't hold onto ski poles because of the skin grafts in my hands.*

Impacts on daily activities	Supporting quotes
Reported by caregivers	
Activities-related impacts	• *He had a special wagon that we used to pull him around because **he couldn't ride a bike**. He just got an adaptive bike last year, was the first time ever in his life he's ever rode a bike. Just things like that that other people spent money on, things that cost $40 and we had to spend $200 because we had to get the extra ultra version.*

Abbreviations: ATV, all-terrain vehicle; TV, television.

Long-term care impacts on survivors

Care-related impacts	Supporting quotes
Reported by survivors	
Needing assistance	• *So yeah, I couldn't walk. My hands were still healing, so I had big bandages on.* ***Couldn't use the bathroom on my own****. Had to ask for help doing that. Couldn't shower on my own. Needed help doing that.* ***Couldn't get myself dressed. Couldn't make a meal. Couldn't clean up the dishes. Couldn't drive. Couldn't get myself from point A to point B.*** *It was essentially a year of rehabilitation post discharge before I could do all of those things. I was essentially like an infant.* • *So there are times particularly with the sight loss where transportation or just kind of, I think the word I used autonomy before, just the ability to.* ***I have to get a lot of other people involved in things I need to do.*** • *The airport, traveling at the airport is the most humiliating experience for me because asking for help,* ***like asking for wheelchair service*** *if you don't ask, if you don't call, and wait, and ask for it ahead of time I've had people just refuse me because I guess because I'm standing there, I don't look like I have partial feet. I don't look like it. I've had like sitting on the plane for extended periods of time if I don't get some kind of just—what do they call it—the bulkhead seating or something I'm just miserable.*
Planning/time constraints	• *Yes, actually, you know, being disabled, it's kind of like you have this* ***extra layer of planning to do whenever you leave the house****.* • *With being an amputee,* ***we've got to get a special chair, a shower chair, and set that all up by going in the shower that we put in****. That's how I take a shower. Sit down for 5 or 10 minutes and probably more, like 5, 10, 15 minutes and shower.* • *Yes, there's been* ***quite some interference****. Since I'm in college, I have to take* ***off for the day because my college is an hour away****. That's one of the reasons we chose the college, which was another interference.* • *But it took me a long time to figure out what those were and how I would adapt to this. I also mentioned that I use a catheter 4 times a day for urination.* ***So essentially blindness and the catheter****, it's a reality. It's not something that…I don't curse meningitis every 5 minutes of the day, or really hardly at all. But I certainly understand and deal with the aftereffects on a minute to minute, second to second basis for*

Care-related impacts	Supporting quotes
	the rest of time for me. I would say it had a dramatic effect on me.

Long-term impacts of IMD on caregivers

Impacts on caregivers	Supporting quotes
Reported by caregivers	
Physical	• *Yeah. Sometimes I'll start going to **sleep** and I'll start thinking about it and I just…I have to pull myself back.*
Emotional	• *He's doing good. I think overall, we…Like I said before, we count our silver linings and we just take life as it is. But it's been by no means easy. There are definitely **times of struggle and times of grief and loss.*** • *It was **traumatic. I think I have PTSD from it still**. I never want to see anything like that again. Yeah, finding him unresponsive gutted me. I still have nightmares.* • *They **called me psycho mom**, because I could get very assertive if my kids were being hurt. When we went to that doctor, he's got a waiting room that's got a bunch of patients sitting there. His nurse said, "Well, he's not even here. He's having a root canal." Well, I've had a number of root canals. I know that's not very pleasant. But I said, "I don't really give a damn what's going on with him right now. Right now, my son's hand needs to be addressed." He came in and he looked at [survivor]'s hand and that was the 1 day that [survivor] said, "Why didn't you people just let me die?"* • *Yeah, I **still worry about him all the time**. I don't know if he told you, but he's studying in [location] next semester.*
Social	• *Yeah. I had some friends who just didn't respond kind of. I don't know, maybe thought I was overreacting or something. Because a lot of people really don't understand what meningitis can do. They think it's like having the flu. So they thought I was overreacting about my kid having the flu, which was absolutely not the case.* • *It definitely gets busy and there's oftentimes where we wonder if we're spread too thin. It's like the other kids, later in life, will be like, "Oh, we had to go so many times to go to doctor appointments." Or, "You guys were gone."*
Work	• ***I haven't worked since**, an actual W-2 job. Everything's been self-employed and hobby type income. That was a big financial hit. We went from 2 incomes to 1. We have been 1-income household for 14 years now.*

Abbreviations: PTSD, post-traumatic stress disorder; W-2, Wage and Tax Statement.

Long-term economical/financial impacts on survivors

Work/education (productivity loss)

Work/education impacts	**Supporting quotes**
Reported by survivors	
Missed education (school/college) days	• *I did. I **missed the last 2-3 months of fifth grade** and the first half of sixth grade. But I did some testing while I was in the hospital and I was able to go back in. So I didn't actually lose any time.* • *But initially, for sure when I was in college, I did go through…I was out. After I left the hospital, I went back to my parents' house for **about 5 months** or so. My objective was to return to my college environment.* • *Yeah, so when I was dealing with my **trying to complete my classes from the Fall semester**, I wasn't able to look at computer screens for extended periods. Anything more than 10 minutes I would have splitting headaches.* • *I was in a music ensemble. It was actually last semester. The whole last year, I was in a music ensemble where we had to stand the whole time. Since that caused me so much pain from standing for the full hour, **I did have to drop that class**. Not in the middle of the year. I made it the full year, but I won't be taking it again.* • *Because I wasn't sure, I had to relearn how to learn. I was, I think a visual learner. I would **look at the board or do things in class, and that wasn't going to work anymore.** So I had to go through a lot of adaption, adaptation, and just kind of **retraining myself to be more of an audible learner than a visual learner.** So that took some time, and there was a lot of anxiety. I do recall initially in the first maybe 6 to 12 months of being back in school just feeling overwhelmed with the impact of all of that, just day-to-day.*
Work/productivity impacts	• *Yeah, so I had a on-campus research job that I was unable to do for the semester that I was on leave, and then when I returned, **I had limited hours just due to the remaining fatigue and balancing returning to school**.* • *Now, again, I'm not disabled, but **I do have limitation. After a full day of something, the next day I need to recoup.** A full day of whatever it is, work or doing things all day, going out and having fun, the next day I definitely need a recoup day.* • *Because I was very…**I was in a leadership role**. So I try to just help others the best I can. If I can coordinate a ride or figure out how to make it work, like in the office for a few*

Work/education impacts	Supporting quotes
	hours, then I will. If not, I'll do it from home. A lot of the stuff I did, I can't do. I did fundraising and a lot of physical activity. ***There were lots of aspects of my job I just can't do. I just try to make it work the best I can.***
	• *It definitely has because as much as…At least the job that I was working before I got…my kidney failed, they were* ***very physically demanding****. I only had so much energy to give. Plus I would get wounds and they'd get infected. It was just…it was too dangerous. So that's definitely affected the amount of money I can bring in myself.*
	• *Then post college, I would say as* ***I was entering the workforce, maybe this would have been probably about 3 years later****, I had a similar anxious feeling about work and just how I was going to be a member of the workforce and keep up with my counterparts.*
Work status impacts	• *Not currently. I was working. I went to nursing school at XX. I got my nursing license and I worked for a few years. Then my kidney failed.* ***I haven't been able to work, mostly due to the physical stuff****. I can barely walk right now. I can't get around very easily. As well as the mental changes, the short-term memory failure and brain fog.*
	• *And there might be things that, because of my sight, that I wouldn't get initially or maybe not even at all. There would be maybe some visual cues or some things that I would not be able to know. It has* ***definitely impacted employment****. I mean, there's been enough times where I've filled out applications and job related things where do I disclose this information or do I not? I've been all around with that type of stuff. I feel like there are times where I have not been given an opportunity because of those disabilities, employment opportunities.*
	• ***I'd love to be able to work 40 hours a week*** *and make 40 hours…have an option for different insurances, not Medicare. Because Medicare keeps me alive. Yes, it's very…that's very complicated in and of itself. But when I was working those few years as a nurse, because I'd done other work, yes, I was sustaining myself. But I was also living in my parents' house. Yeah. I always* ***wish I could do more in terms of physically at work****.*
	• *Definitely. I mean, because I can't even…I can't stand to work places, and I, you know, and then my…it hurts to even sit for extended periods of time at some aspects, and so if I didn't have artwork right now when…I don't know, I haven't…my artwork sales aren't the greatest, but actually they're pretty much nonexistent right now, so I am looking for something.*

Work/education impacts	Supporting quotes
	• *So yes, I thought I did, but I really didn't.* ***I tried a couple of part-time jobs****, I'd say, for the first…after those 4 or 5 months. Then, for like another year, let's say, after that, tried to really get back into the workforce part time.* ***It took me a while to get back to a more legitimate, let's say, 30-hour-week job****.* • *Maybe…****now I just work as a volunteer****. So, I mean, you don't really ever recover from this level…from being not disabled to being a quadruple amputee who has…*

HCRU and long-term costs associated with IMD

Therapies used by survivors due to their sequelae

Therapy type	Supporting quotes
Reported by survivors	
Physical therapy	• *Yeah, I'll see her this year at some point, I'm sure. I saw a **vestibular physical therapy** person a couple of times last year.* • *I have tried everything you can think of from **chiropractors to physical therapy** to…I have not had any kind of surgical procedures to my head or neck, and I don't think that I would allow…* • *I had like physical therapists and whatnot who would come to the home. If that's what you mean by home care.* • *I usually take care of at home. But I mean, there were points too where I've injured myself where I needed to see a **physical therapist** so I can get the stretching techniques to prevent it from happening again.* • *I've had to get **physical therapy** for my neck, to try to get help or help when I stand too much. I've made a rule for myself that I can't go more than 30 minutes standing without sitting down for just a little bit. Even if that means going and sitting on the floor somewhere, I just have to do it.* • *I needed to go to **physical therapy**. I don't really remember how often it was, but it was a few times a week. At physical therapy, they helped me relearn how to use my left hand, and a little bit of walking.*
Psychological/psychiatric therapy	• *I've been **talking to a therapist and getting some strategies**. So breathing techniques and looking around the room and identifying specific things or specific sensations to ground myself.* • *I do…actually**, I see 2 therapists a week**. Because I do feel like I need extra support. I'm lucky that I can have that.* • *I had a **therapist while I was in the hospital**, but after discharge, I didn't go to therapy, no.* • *I see a **therapist at school** when I'm at college.*
Occupational therapy	• *Yes. When I was getting well again, I did **OT and PT**. I was like I want to relearn everything. I had to relearn everything, how to zip a zipper, how to eat, everything. I took that…that was incredible to overcome. I was like, I'm never getting back there again. I'm never going to be back at square one unless…So I'm*

Therapy type	Supporting quotes
	good at driving. I have a clear record. [laughter]. No tickets, no nothing. • *The **therapy and stuff, occupational, physical** all ended within 12 months of being hospitalized that was all done.*
Speech therapy	• *I say was because I actually went completely deaf in that year 2 years ago. I'm very lucky that it was my bad ear that I lost all the hearing in. There wasn't much left. Then, like I said, my balance was very affected. I had to do a lot of **physical therapy and occupational therapy and speech therapy t**o learn how to talk again.*
Medical rehabilitation	• *Once out of the hospital, I did go to an **outpatient rehabilitation clinic** for probably about 2 months. And those were things that we worked on among others. Balance was another one that we've worked on. Walking, I used what's called a gait belt, which is kind of like a karate belt. If you've seen a karate belt, like a black belt. It's kind of thick nylon like that. It's meant to have a therapist on either side or both sides of somebody walking with him. Then they would hold onto the belt to keep me from falling. So I used a walker and then I used some other devices to help get me mobile and walking.*

Abbreviations: OT, occupational therapy; PT, physical therapy.

Expenses related to HCRU as incurred by survivors

Care and treatment in long-term	**Supporting quotes**
Reported by survivors	
OTC (not covered by insurance)	• *Certain things like **supplements, some equipment**. Like we bought a wheelchair just for dialysis so I didn't have to take my wheelchair out of the house. A lot of med copays. There's more stuff over the years, but right now it's not so bad.* • *That's correct.. **reusable catheters** and there are disposable catheters. My original prescription at the height of the hospital is for reusable ones.* • *For pain, instead of prescription medicine—because they had me on…Early on, I was on fentanyl and stuff. Now I use legal medical marijuana through the state. That is not covered. **That is all out of pocket**. Yes, I guess that would fall under there.*
Prosthetics/hearing aids	• *Yeah. Yeah. I'm working on **another pair of leg braces**, so that's a couple thousand dollars out of pocket. Trying to think of what else…I mean, that's the big one.* • *Yeah, I have to buy a new **hearing aid**. I haven't gotten a new one since 2007, for a lot of reasons. But one of them is money.* • *Then there's specialty things that I just can't afford. Like there's these…What's it called? I want to say…These **prosthetic hand** things that I wish I could get but they're just…it's just out of my reach. Naked Prosthetics is what it's called. To try to give you extended fingers, to be able to grip. Insurance doesn't cover that so there hasn't been out of pocket because I can't afford it.*
Homecare	• *So they had to buy a…They ended up buying a **metal chair** for our bathroom so that I would be able to sit while I showered. And they bought a new **reclining chair** for me because I needed a place to sit because I couldn't sit up on the couch. But, yeah, no medical implements or anything like that, I don't think.* • *The transition for leaving…I was still not able to walk, and my left hand was still not really usable, so we needed a **wheelchair**. We needed a hospital bed in our living room in the house. We needed a **ramp** to get in the front door.*
Medication expenses	• *It definitely has a very large impact on my life. I'm one of those people that I've been on **antidepressants** since I was 11. It's just a back and forth sometimes. That will work a good amount of time, but then it will stop working.*

Care and treatment in long-term	Supporting quotes
Medical procedures	
Blood tests	• *That comes with a lifetime of…You've got to take medications every 12 hours on the dot, every day, forever. You have consistent follow-up with the transplant team and the PCP and everybody. There's a* ***lot of lab tests and bloodwork****. Just check-ins. They have to check the levels of the medicine in your body and adjust it. There's a lot that goes on that takes up a lot of brain space. Of course, if…I'm trying to think. Sometimes they have you do biopsies to check on the state of the kidney and this and that. Pretty intense.*
Follow-up medical check-up	• *Through time, I do have to have* ***checkups*** *with my bladder situation and my eye condition. I mean, some of that it's probably 50/50 as far as if that is covered or not by medical plans going forward.*
Dialysis	• *Yes. I was on* ***dialysis when my kidney failed originally****. The only treatment for that is continue dialysis or have a transplant. Luckily, I was able to receive one from…It's actually funny. It's my adopted dad. He matched me. He gave me his kidney in 2002. He's an incredible person.* • *And I* ***was on dialysis 10 hours a day****. It wasn't the best environment. I just wasn't really thriving.*
Hearing tests	• ***Sometimes it's a copay****. Sometimes it's with someone who doesn't take insurance, blah, blah, blah. But that's something that I've always had to…I've done that. I've done speech therapy. Annual hearing tests, see where my hearing is at.* ***There's a lot of expenses of things that I'm still dealing with. Even though I had meningitis in '87, I'm still managing the aftermath of it.***
Stress tests	• *Yes, most of the time, it is. I'm on a transplant list right now, so I have to go a certain amount of time. There's a lot of testing I have to keep up to date. Like I just booked a* ***stress test****. It's like constant right now.*
Interventions at wound clinic	• *What I do is I prevent them to the best of my ability. If I get one, I have to go to a wound clinic. I usually have* ***to go there every week*** *until it's healed. Yeah. I have gotten infections. I have been in the hospital and had to receive like IV antibiotics and just be there for a while, which is always.*

Abbreviations: HCRU, healthcare resource utilization; IV, intravenous; OTC, over-the-counter; PCP, primary care provider.

Insurance

Insurance related findings	**Supporting quotes**
Reported by survivors	
Type of insurance and its impact	• *Have an option for **different insurances, not Medicare**. Because Medicare keeps me alive. Yes, it's very…that's very complicated in and of itself.* • *Yeah. Well, unfortunately, in this country, **when you're disabled, there's not a lot of options for you to become a wealthy person with Medicare and MassHealth** and how it's set up.* • *Then I think my **parents struggled with insurance**, so there was a little bit of a break.* • *When I went to the mental therapy for that 4-year or 5-year period after that was not covered either, so I did pay for those myself. And some of this again was under my parents' insurance, so I don't really have a good feel for the exact hospital stuff. And the therapy that I went through after that, which was pretty rigorous, I don't think my parents were burdened by the cost of that. I believe their insurance paid for that. I do know there are things that weren't paid for that they got involved in. But I think most of the medical necessary stuff, I would say at least **90% to 95% of that was covered by the insurance plan**.* • *I had **full commercial insurance through my employer for a while plus Medicaid**. Yeah. I was able to support myself. Was laid off in 2009, spent a year working part time and living with my parents. That was not really related to my injury. That was because of the recession. And then started working full time again in 2010. Yeah, towards the end of 2010 and have been working full time ever since with employer-based health insurance.* • *As for the bill and **insurance, it actually did become a little bit of a problem**, but after working with insurance and all that stuff, it turned out okay. But at some point, I got a bill for like $500,000 or something for my stay and my…Yes, some kind of ridiculous bill. After calling insurance and all that stuff, it worked out okay. My mom had to work a restaurant job just to make ends meet at a certain point.*
Insurance coverage	• *They would not cover…They will not cover my face. **They would not cover reconstructive surgery on my nose** because they claim it was rhinoplasty like I was getting a nose job instead of the ability to breathe out of my nose. I think that…*

Insurance related findings	Supporting quotes
	• *I believe the majority, I would guess no less than **80% of that was covered by our health insurance at the time**. I don't think it was a major burden on my parents.* • *My nose, it looks pretty good now, but my nose, inside my nose where they had reconstructed my nose my breathing passages aren't the greatest. When my doctor, my plastic surgeon **was trying to work on that the insurance would not cover** it. They said it was a rhinoplasty, and they would not cover my nose getting open so I could breathe. My surgeries could be never ending if I would let them be. It's just how much emotionally I can handle, and financially it's not really an option.* • *My next effort would be some kind of a…one of those pain shots. I tried to get Botox for my neck and my head for the tension headaches I get from the neck and head pain, but I **can't seem to find someone that would run insurance for it**, so it's just really expensive.* • *Through time, I do have to have checkups with my bladder situation and my eye condition. I mean, some of that it's probably 50/50 as far as if that is covered or not by medical plans going forward. But I can tell you for sure, **my catheters are not covered**. I do buy those myself. It's never fun buying those.* • *The therapy and stuff, occupational, physical all ended within 12 months of being hospitalized that was all done. Including the mental therapy initially, **those things were covered.***
Copay, deductibles, and OOP expenditures	• *You're always wondering **am I going to have the copay. How much is this going to cost?** Oh, I need a new wheelchair. It's very…it takes up a lot of resources, being disabled.* • *I'm **not sure how much coverage I would get**, and so if we have a deductible, and I guess…You just don't know. It's just hard to say. The fat grafting is liposuction, and then they put the fat back, and so I don't know why they thought that was so much easier to cover instead of helping me breathe, but it will always be…Or medication, you know, having…I try…* • ***Sometimes it's a copay. Sometimes it's with someone who doesn't take insurance**, blah, blah, blah. But that's something that I've always had to…I've done that. I've done speech therapy. Annual hearing tests, see where my hearing is at. There's a lot of expenses of things that I'm still dealing with. Even though I had meningitis in '87, I'm still managing the aftermath of it.*

Insurance related findings	Supporting quotes
	• *Then **there's specialty things that I just can't afford**. Like there's these…What's it called? I want to say…These prosthetic hand things that I wish I could get but they're just…it's just out of my reach. Naked Prosthetics is what it's called. To try to give you extended fingers, to be able to grip. Insurance doesn't cover that so there hasn't been out of pocket because I can't afford it.* • *So I don't even know that I'll be able to afford my secondary medical. That's out of pocket, **like $700 a month**. I don't even know that I'll be able to afford it when I turn 65. So I think that that's my biggest concern.* • *When I went to the mental therapy for that 4-year or 5-year period after that was not covered either, so **I did pay for those myself**.* • *I mean, they were covered. They were covered, but you have a deductible, you know? You have copays. They're covered, **but you have cost sharing.***

Abbreviations: OOP, out-of-pocket.

Out-of-pocket expenditures

Miscellaneous expenses incurred by survivors	**Supporting quotes**
Reported by survivors	
Home adjustments	• *We needed a **hospital bed** in our living room in the house. We needed a **ramp** to get in the front door.* • *Yeah. For sure. I had some **ramps built. Shower chair**. It sounds like I'm breaking the house apart but things to prevent hitting the walls. Stuff like that. Those are just a few examples.* • *So they had to buy a…They ended up buying a metal chair for our bathroom so that I would be able to sit while I showered. And they bought a new reclining chair for me because I needed a place to sit because I couldn't sit up on the couch.* • *Yes. We needed to **widen the bathroom entranceway** to make sure that my wheelchair can go through. Oh I think for the renovation for the bathroom, I think it was almost I think 3 or 4 grand.* • *No. Other than putting **a bench in the shower** and that's like a portable bench. It's not like something we built into the shower. It's an off-the-shelf thing from Walgreens. It cost about $50.* • *Oh yes. Yes. The **ramp was made by a friend**, just because we needed something to get me in the house. [laughter] The ramp was…Yes, my ramp was a makeshift…just a piece of wood to help me get in the house. Then, yes, we had to rent a…Or I guess…I don't know what we did, but we needed a hospital bed in the home, so we had one of those. I basically lived in the living room of our home for 4 or 5 months.* • *So I think there might be things that I have to pay for, like in the home, to make things easier for me and **lower shelving and hairdryer stands**. A lot of things that people just don't think of.*
Disposables	• *But the health insurance that I've had in the past would not cover disposable ones. And the health insurance I have currently, **the health plan also does not cover disposable**. I'm not sure if they cover reusable ones, but I'm not using those anyway. It's just super inconvenient. Just a bladder infection waiting to happen. So I use disposable ones and I have since and for a long time.* • *And there's different types of those, but the cheapest ones are about 50 cents apiece, and that's a whole different topic. But the ones that are a lot more mobile that I can take with me on the go that are fully able to just walk in somewhere and do it and walk out without any major fiasco are about a $1.50 a*

	piece. So 4 times a day, depending upon which one I'm using. ***It could be as little as $2 a day, or it could be as many as like $8 a*** *day. Just kind of depends.*
Maxing out deductibles	• *So yeah, there's a lot of years where* ***I'll max out my deductibles*** *because I have to have another small surgery, or I get an infection because I get a sore in my foot, or I have to have new leg braces made, or I have to have my leg braces altered, or I need to get new liners for the leg braces. Yeah. I've spent tens of thousands of dollars out of pocket over the last 20 years.*
Financial support/disability benefits	• *I will say, there are other resources there in the state that I live, which is XX. There is a XX commission for the blind, which does supply the software I mentioned to you previously, the magnification software. Initially during my college years and a few years after that, supplied the software and other braille and/or other trainings that if I chose to take them or not, they did supply those. That was certainly helpful then. As of today, I'm not sure if those resources are available. I do have to get software updates every year or 2, and my employer does pay for those, so I don't pay for those out of pocket.* • *Then also my Medicare and the secondary insurance. I think that I just…I think I have it under control and well-managed and why it's worked for me. Also, I have a long-term disability but that ends when I'm 65.*

Abbreviations: XX, personal identifiable information redacted from interview transcripts.

General financial impacts

General financial impacts	Supporting quotes
Reported by survivors	
Financial struggle	• *I have to just try to figure out how to budget and manage that and streamline it so I'm doing things the most cost effective.* • *There's a lot of expenses of things that I'm still dealing with. Even though I had meningitis in '87, I'm still managing the aftermath of it.* • *I think it's…I mean it's a struggle. I think it's tough trying to figure out all the pieces to make it work. I think if you have the basics like insurance and housing and a good medical team and an incredible support system and financial means…I mean I struggle sometimes because I am on disability. But I keep my expenses as low as I can. Before I got sick, I could do more and more exciting things and eat out more. Now it's just all different because you're more on a limited income.* • *Then in college it just really…I mean, obviously I still learned all that I could possibly learn, but I think that I have student loans, and I'll be impacted by the physical limitations that I had in college for the rest of my life. I mean, it'll probably haunt me forever, and to this day, like I said, I try to look online and go like, oh, I wonder if I could do that, or I wonder if I could do that, or just trying to find some way to earn money so I can help even get to our deductible so I can get…*
Savings	• *So it's always been a struggle for me to save money. I have been on Social Security throughout the years when I wasn't working or parts of college when I wasn't working. But it's very stressful. You're always wondering am I going to have the copay. How much is this going to cost? Oh, I need a new wheelchair. It's very…it takes up a lot of resources, being disabled. Takes up a lot. Yeah, I do worry about money all the time. I'm always worrying about money.*
Cost of future treatments	• *I tried to get Botox for my neck and my head for the tension headaches I get from the neck and head pain, but I can't seem to find someone that would run insurance for it, so it's just really expensive.* • *My surgeries could be never ending if I would let them be. It's just how much emotionally I can handle, and financially it's not really an option.*