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Neither Dazed Nor Confused

The stories behind a world expert's battle to prevent delirium

Guest: Sharon Inouye

Host: Stephanie Dutchen

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Dutchen: Hello, and welcome back to the Harvard Medical Labcast, brought to you by the Harvard Medical School Office of Communications. I'm your host, Stephanie Dutchen. With us today is Sharon Inouye, a geriatrician who has revolutionized our understanding of delirium.

Once upon a time, not too long ago, medical professionals believed that a subset of elderly patients in the hospital were just going to become delirious and there was nothing anyone could do about it, but Dr. Inouye demonstrated that, to the contrary, delirium can be prevented. Her many accomplishments have included creating the world's most widely used checklist to identify delirium and developing a program that hundreds of hospitals now use to reduce cases of the condition. Sharon, welcome.

Inouye: Thank you, Stephanie. I'm really excited to chat with you.

Dutchen: I am also very excited to speak with you today. Before we dive into the details of what delirium is and what we can do about it, let's get the title soup out of the way. So, you are a professor of medicine at Harvard Medical School and director of the Aging Brain Center in the Marcus Institute for Aging Research at Hebrew SeniorLife. Did I get that right?

Inouye: That's right.

Dutchen: Okay.

Inouye: Thank you.

Dutchen: And you have earned a list of recognitions as long as my arm. I think my favorite one might be that in 2014, Thompson Reuters named you as one of the, quote, World's Most Influential Scientific Minds, so congratulations on that.

Inouye: Thank you.

Dutchen: Okay. So, our unofficial theme this season on the Labcast is journeys, the paths people have taken to get where they are now, and you've had a bit of an unconventional path, turning away from and then back to medicine when you were young. And I think, if all goes to plan, we

are going to talk about your father and poetry and writing and a secret musical talent and a recent foray into health policy. So, does that sound about right?

Inouye: That sounds about right, Stephanie. It does sound like a journey.

[MUSIC PLAYING]

Dutchen: I'd like to start by asking you about your dad, because he sounds pretty amazing.

Inouye: Sure. Well, my dad, his name was Mitsuo Inouye, was my hero and my role model, he's really the reason that I decided to pursue a medical career. When I was a young child, my earliest memories were wanting to spend more time with my dad, and he was a very busy general practitioner in Southern California.

Dutchen: So, he was a doctor himself?

Inouye: He was a doctor himself. And he was the kind of old-time doctor that made house calls, was on-call 24/7 for his patients, so he wasn't around at home a lot. So, when I was about 3 and 4, when he would get up to go out, I would hang on his leg until he was forced to take me with him, wherever he was going. So, I spent a lot of hours with him on rounds in the hospital...

Dutchen: Oh, wow.

Inouye: ...going to see patients. He would, on the weekends, drop me off in the newborn nursery and I would hang out with the nurses, and I really developed a love of medicine way back then.

Dutchen: I read somewhere that you said that you grew up in something of a traditional family where women were maybe expected to stay home, or at least not to become doctors?

Inouye: Yes. Yeah, that was very true. So, I have two brothers and one sister who's quite a bit younger than me, and I know my two brothers had a lot of pressure to become physicians, and I said, "Oh, but I want to," and they said, "Oh, no, Sharon. It's not for you." And my mother didn't work, and my grandmother didn't work, and it was kind of the way in a more traditional Japanese American family, particularly when your father's a physician.

Dutchen: I noticed that on your Twitter bio you describe yourself as "chief troublemaker." Is this where some of it stems from?

Inouye: Probably. That's actually what my team calls me, and my family, truth be told. I think I always had a bit of that ... I guess it's rebellious spirit or free thinking, just if people told me I couldn't do something, then I would say, "Why not?" And I remember my grandmother washing my hair when I was little, like maybe 5 or 6, and she was saying, "Such a good brain on your shoulders. Too bad it's going to go to waste," and I was like, "It's going to go to waste? What does she mean?" and I just said to myself, "I'm never going to let it go to waste." So, yeah, so I

think that was a little bit like those strictures being placed on women and what you could do or what you couldn't do in life. I didn't understand it.

And I have to say, though, that even though I wasn't encouraged to go into medicine, once my family saw that, many years later, that I wanted to, they were very encouraging and supportive. It's just that they never... it never dawned on them that a woman would want to do that, so they were very supportive once I declared my intentions.

Dutchen: And your brain has not gone to waste, and a lot of people, I'm sure, are very grateful for what you've done.

[MUSIC PLAYING]

Dutchen: So your father had done some pretty impressive and compassionate work with survivors of atomic bombings in Japan.

Inouye: That's right.

Dutchen: And I saw in your CV that you have also won some awards for humanism in medicine, and I wondered if you could talk a little bit about what he did and whether you see your compassion as having stemmed from his.

Inouye: Ah, that's a really good question. So, my father worked for years trying to get health care coverage for Hiroshima bomb victims, who were called the *hibakusha*. So, these were American citizens who were living in the Hiroshima area during the atomic bombs, or some of them were people who married American citizens and then came back to the States. So, my father provided free care to hundreds and hundreds of *hibakusha*, and he also did political advocacy.

But you asked me about the roots of my interests and compassion and humanism, and I think it did take root on those rounds with my father and watching how he was with patients and how he dedicated his life. And when he died, there were over 750 people at his funeral. I can't tell you how many people came up, and all the stories of, "You know, your father saved my life and never charged me," and I heard that like a hundred times, and it just really made me feel so proud. You know?

Dutchen: That's incredible.

Inouye: Yeah.

Dutchen: We're going to come back around to the story of your father, because it's, uh...

Inouye: Okay.

Dutchen: ... a pretty sad ending. But back to your growing up and your career path, all of this passion for medicine, and you went off to college and you studied English and music. Tell me what's going on there.

Inouye: So, yes, through high school, I got so interested in English literature in the biggest way, writing in the biggest way. So, then when I went to college, I maintained that interest in literature, and it was really fun. And I also fell in love with baroque music.

Dutchen: Baroque music.

Inouye: Yes, harpsichord. And I had been a pianist all my life, but when I got to college, I decided to become a harpsichordist.

Dutchen: Like you do.

Inouye: Yes.

[MUSIC PLAYING IN BACKGROUND]

Inouye: Yeah, so I took lessons in college and became kind of fanatic about it. I was playing harpsichord like six hours a day, missing all my meals.

Dutchen: Oh, wow.

Inouye: Yeah, I was a little bit ...

Dutchen: Booking all of the hours in the practice room?

Inouye: Yeah, in the music room. Mm-hmm.

Dutchen: Okay, so wait, but we're missing part of the story here ...

Inouye: Yes.

Dutchen: ... which is that you built one ...

Inouye: I did.

Dutchen: ... yourself.

Inouye: I did. So, after about a year of playing the harpsichord, and I was also performing in a small chamber group, I asked my dad, "Could I have a harpsichord?" I invited him to my next concert and he came and he saw that I was really serious. So, he let me buy the \$300 kit, which was kind of a joke, because in those days, girls didn't even get to do wood shop, so I didn't know the first thing about managing a drill or a saw or a hammer, and there wasn't internet and

YouTube to teach you, you know, so I checked out books from the library, I remember the *Reader's Digest Guide to Carpentry*, and I taught myself how to build a harpsichord.

Dutchen: In your – in your dorm room?

Inouye: In my dorm room.

Dutchen: Did you have a roommate?

Inouye: Fortunately I had a single, thank goodness.

Dutchen: Could you and the harpsichord fit in your single at the same time?

Inouye: Barely. Barely. I had to downsize my bed, and yeah, and ... yeah.

[MUSIC ENDS]

Inouye: But I still did my premed classes.

Dutchen: Oh, okay.

Inouye: Because you had to do science at Pomona College, which was actually a good thing, and I actually did love the sciences, so I still did them, but I was going to be an English professor.

Dutchen: Okay.

Inouye: After I did the Peace Corps.

Dutchen: So, what happened?

Inouye: So, what happened was... You'll understand the pattern now. I had a bunch of friends who were in the year ahead of me and they were all applying to medical school, and they were all guys, too, and they dared me to apply a year early, and I said, "Well, number one, I'm not premed, and number two, I don't really want to go to medical school, and they said, "That's perfect. Let's just see if you can get in."

So I applied a year early, never, never, never thinking I would get in. And I remember when I wrote my essay, it had all little embedded boxes with poetry in them, and then my little essay dispersed amidst the little poetry squares.

Dutchen: Poems that you had written?

Inouye: Yeah, my poetry. Mm-hmm.

Dutchen: Poems about medicine?

Inouye: No, they were poems about meditating on life at the top of a mountain and poems that were like in kind of a slang dialect that I had made up. And I think that, now knowing about reading hundreds of medical school applications, I think mine might have stood out.

Dutchen: Do you still, like, embed little poems in your journal submissions?

Inouye: I don't. I don't, actually, except I couldn't resist when I had submitted my first really big grant to the NIH, and it got rejected twice, and then the third and final resubmission, and this is now ... we're talking about almost a three-year process to get it funded, they had said, "Sharon, this study is too complicated and you have to narrow it down to one intervention." I started my response to the NIH with an H. L. Mencken quote. You only have this tiny space to respond, but I put, "For every complicated problem, there's a simple solution ... and it's wrong."

Dutchen: And they funded you?

Inouye: And they funded me. So, yeah, we still every once in a while ... it's not poetry, but, you know, you have to put in something that makes people see the message.

[MUSIC PLAYING]

Dutchen: All right. Well, let's steer toward your research, the work that you've done, your clinical work.

Inouye: Sure.

Dutchen: You get out of medical school -- you go to medical school, you get out of medical school. Your focus at the time is internal medicine?

Inouye: Yes.

Dutchen: And somehow you end up in geriatrics?

Inouye: Yes.

Dutchen: And then in geriatrics you start to get pulled towards this problem of delirium, so let's talk about that. And actually, as we talk about that, let's make sure that we all know what we're talking about when we talk about delirium, because ... I mean, my understanding of it is sort of like an acute confusion...?

Inouye: That's right.

Dutchen: But I'm sure there's more to it than that.

Inouye: Right. So, delirium is an acute confusional state, and you can think about it like acute brain failure. So, what happens when someone is delirious is they seem to be out of touch with what's going on around them. They can seem very confused and disoriented, they can also seem

to not be alert at times. And typically delirium occurs in the setting of acute medical illness, hospitalization, surgery, major, major critical illness, for instance. And so it is associated with something medically, typically, going wrong. So, it's a sign of the brain reacting to this serious medical condition.

Dutchen: Okay. I was looking up statistics before, let me see, from the American Delirium Society that estimates that more than 7 million hospitalized people in the U.S. get delirium each year?

Inouye: Yes, it's extremely common, extremely common.

Dutchen: Yeah. And some of the trouble with that is that people end up staying longer in the hospital, they may get more complications, they may die at a higher rate in the hospital or when they get out of the hospital.

Inouye: That's right.

Dutchen: So, that's not great.

Inouye: That's right. Delirium is associated with really serious complications, so that's why it's very important to know about it and also to try to prevent it from happening.

Dutchen: All right. So, what drew you in?

Inouye: Yeah, so when I first started in internal medicine, so even before I was a geriatrician, so literally I had just finished my medical training, and I was at the West Haven VA Hospital as an internal medicine attending.

Dutchen: That's in Connecticut?

Inouye: In Connecticut. And also, I was working on a geriatric unit as well. But this was the very first time I'm an attending physician, and that means you're in charge. I'm responsible for a team of doctors-in-training and medical students, and I'm overseeing the care of about 40 patients. And during the course of that first month, taking care of all the things you see on internal medicine—congestive heart failure, heart attacks, strokes, pneumonia, cancer, all the bread and butter on a medicine service—I found that I was able to do that, I felt pretty confident, our teams were doing a good job.

But then I noticed there were these older patients who got acutely confused while they were in the hospital on my service. And six of them, I remember, that first month, became acutely confused. And they hadn't been confused when they came in, they got very confused during the hospitalization, and they all ended up not doing well. Two of them went to the intensive care unit, two of them ended up dying, two of them ended up going to nursing homes. These are not the things you want to see happening to your patients.

So, while it was happening, I remember I reached out to my colleagues and to the chief of my service, and I said, "What is this about these older patients who become confused while they're in the hospital?" And they all said to me basically the same thing, which was, "Sharon, that just happens to older patients when they come to the hospital. Don't worry about it. We just see it all the time, don't worry about it."

And at the end of my month, I couldn't stop worrying about it, so after I was done working 24/7, I went to the medical record room and I pulled the charts of all those six patients, and I these huge graph papers and charted out everything we did to those patients every single day, and from my notes, when that confusion started, whether they were confused each day, and I had written down every medication, every procedure, everything we did to every patient. And I began to notice patterns of things that we did, like certain medications, like pain medications or sleep medications or immobilizing these patients or giving them Foley catheters with urinary tract infections, and I saw these patterns happening. It was just six patients, but I really tried to figure out, "Okay, what caused this?"

So, I saw these patterns and I went to bring those to the chief of my service and I said, "I think that we caused this to happen, the confusion..."

Dutchen: Uh oh.

Inouye: "...We contributed to it," and he nodded his head very patiently and said, "So, Sharon, I think you've noticed something, and this is a really good point. Why don't you give a lecture to the house staff on prudent drug management in older adults." I said, "Great! Great! And then?" And he said, "Well, let's start there." I think he thought that would take care of the problem, the problem not being the confusion in the patients, the problem being the overeager young attending that wanted to change all medical care in the hospital.

So, that was what started me on my career, really, in thinking about delirium. So, I had to, obviously, finish out my year as an attending, and then I went back to get training in how to do research, because those big graph papers just weren't going to make it, right, and, yeah, and then I went back and also got geriatric training.

So, it was really the interest in what was happening to these patients with delirium that also got me very interested in the geriatrics, besides the fact that I loved working at the VA Hospital and taking care of that population, and at that time, most of them were World War II vets and were elderly, yeah.

Dutchen: This was in now the early to mid-1980s, and a couple decades go by and you have done so much to help people understand what delirium is, what the risk factors are, and how those risks can be mitigated. So, what are those?

Inouye: Yes. So, the risk factors for delirium, there are a lot of them, but some of the key ones we've identified are cognitive impairment, so people who have any degree of memory loss, even in early stages, ranging up to more severe stages like Alzheimer's disease, that's a very strong

risk factor for delirium. So, if you're a caregiver of someone who has dementia or Alzheimer's disease, it'd be very prudent to get to know our website so that you know what can be done.

Dutchen: And that website is...

Inouye: HospitalElderLifeProgram.org, all one word.

Dutchen: H-E-L-P, HELP.

Inouye: HELP, yeah. Exactly.

Inouye: The other important risk factors to know about are vision and hearing impairment, dehydration, multiple chronic conditions, a major surgery—which means that general anesthesia and a prolonged hospitalization are planned, two or three or more days—does pose a risk for an older adult, and being on multiple medications.

Dutchen: So, what can people do if they're listening to this podcast and maybe they have a loved one or one day they have a loved one who becomes delirious when they're hospitalized, or they're a researcher or a clinician and they want to do what they can to help a patient or help large numbers of patients?

Inouye: So, starting with family members. Please know that if you see changes in your loved one, if you see that they're not making sense or you're worried or they're just not themselves, please bring that to the attention of your health care providers, and please stress that it's really important that it needs to be looked into. Because really, the family members are the ones who recognize the changes before anybody else does.

Then for clinicians, health care providers, I would just encourage everybody to get as knowledgeable about delirium as possible. It is very hard to recognize sometimes, in the early stages, because of the fast pace of care, because we don't have time to do a cognitive assessment. And so there are hints, again, on the same website of how to recognize it, how to recognize it quickly, and what to do if it occurs. There's a lot we can do to prevent delirium.

And then to researchers, I do hope that delirium can become a more important part of research, and we have resources on our HELP website that we already mentioned, we also have another program called NIDUS, N-I-D-U-S, and if you go to nidusdelirium.org, you can learn about a wealth of resources we have to help researchers who are interested, including funding, training, pilot grants, measurement tools, et cetera.

Dutchen: Thank you. So, to put that another way, what are some things health care delivery teams can do to prevent somebody or try and prevent somebody from sliding into delirium?

Inouye: Yes. So, that is what our Hospital Elder Life Program does, is it focuses on those interventions that I've mentioned, and really provides staff and trained volunteers to provide things like orientation, so reminding persons where they are, providing their schedule up on a white board, for instance, in the hospital room, providing a clock and a calendar so people can

stay oriented. We provide therapeutic activities, which means fun activities that keep people cognitively engaged while they're in the hospital.

Being in the hospital can be very socially isolating, very disconnected, family can't be there all the time. And so providing fun things for people to do while they're there and tailored to their interests. So, reading materials, crossword puzzles, music that they like, games and activities, crafts, those are exceedingly important while a person's in the hospital.

We provide vision and hearing adaptations, we teach the staff how to communicate with someone who has severe vision and hearing impairment, we prevent dehydration, providing fluids by mouth if they're allowed to take them. We get patients up and walking three times a day. That's really important, not to stay in bed all the time. Staying in bed really leads to loss of functioning and mobility. And addressing medications and reviewing the medications on a daily basis.

Dutchen: Now, I read a number, and the number was that ... two numbers. One number, HELP has now been adopted in something like 200 hospitals. Second number, that it's reduced instances of delirium by something like 40 percent?

Inouye: Yes.

Dutchen: Wow.

Inouye: Yes, both numbers are true, and it's probably way more than 200, but we stopped counting at 200, but that was a lot of years ago, and I know there's a very big HELP movement. We currently actually have 4,000 people registered on our website.

Dutchen: That's awesome.

Inouye: Yeah.

[MUSIC PLAYING]

Dutchen: An important theme in this work has been teams, things have to be done in teams, and this is where I think we can get back to the story about your dad.

Inouye: Yes.

Dutchen: Please tell us more.

Inouye: Yes. So, it was back in 2010, my father was hospitalized for a major surgery, a cardiac bypass surgery. He actually was still working and collapsed on his hospital rounds, and he was in his late 70s at that time. And he was admitted to the hospital, received emergency cardiac catheterization with contrast dye that actually caused him to go into renal failure, because he was a diabetic and that's a risk. His kidneys never recovered, he had to be started on dialysis, and he underwent major bypass surgery.

And I was there at his bedside from the time of his surgery, and my father emerged from the surgery and became acutely confused. Didn't know where he was, was hallucinating, seeing things that weren't there. It was really, really difficult to watch.

And I was spending all of my days, every day, trying to speak to all the different physicians, nurses, teams that were taking care of him, because he was getting care by the cardiac team, the surgery team, the renal team, the dietary team, and rehab and infectious disease, and I couldn't get to all of them every day. And they were all prescribing different things that were making him more confused, and he wouldn't eat because he hated the food, and it was this renal-cardiac-diabetic diet that was terrible, so he lost so much weight, and he was already thin to begin with. So, it was just really horrible and difficult to watch.

And I realized ... I was sitting there, and my mantra was, "How could I let this happen? I'm a world's delirium expert and I can't prevent it in my own father." I know everything that needs to be done, and I couldn't prevent it in my own father. And I realized, it just hit me that day like an epiphany, that no one person, even a world's expert on delirium, can prevent delirium by themselves. You have to have a team, you have to have an enlightened, motivated health care system, you have to create systems that make it easy to prevent delirium. So that's what we try to do through the HELP program is make it easy to prevent delirium.

Dutchen: That's heartbreaking.

And yet you remain optimistic and active, and you made some more interesting career decisions following on what happened in that hospital. You went down south to Washington, D.C., and what happened there?

Inouye: Yeah, so with that epiphany that I had around my father, it took me a few years, but I realized there's only so much you can do through clinical care and through research that, really, to make big change, you had to learn how to make policy change. So, I became a Health and Aging Policy Fellow and I went down to D.C. and learned about how policy is made in our country, about the different levers we have to change policy, and I worked at the Centers for Medicare and Medicaid Services and also at their Innovation Center to really try to think about how we could do things differently.

And what I did learn and what helps keep me really optimistic is that there are so many dedicated and committed people who want things to be better, who want to see change for the better, and are very motivated to make the change. And I've also seen other countries where they do health care for the elderly much better than we do in the United States and who already focus on delirium. So, I remain optimistic that we can do things here.

[MUSIC PLAYING]

Dutchen: Research-wise, you're principal investigator on at least one study looking at what delirium is tied to, what's the relationship between delirium and dementia. What is exciting or motivating to you about focusing on that now?

Inouye: So, I think it's really critical to advance the field, to understand the relationship between delirium, which is this acute confusional state that's typically been considered to be transient and reversible, and a chronic cognitive state like dementia that's progressive and that's irreversible. And previously, it had been thought that they were independent of each other. Even though we knew dementia was a risk factor for delirium, it wasn't thought that delirium itself could contribute to a dementia or make a dementia worse or make a dementia progress more rapidly.

So, those are areas, I think, that are critical to explore and understand, and we have a large grant from the National Institutes of Health to try to investigate this interrelationship and to try to sort it out. And I think it's key, because if we knew delirium was going to lead to a dementia, at least in some percentage of people, and we also know that we can prevent delirium, then do you see, it changes the whole story of dementia and Alzheimer's disease?

Dutchen: Mm-hmm.

Inouye: And the fact that we're not paying attention to it right now in the Alzheimer's field, I think, is a big oversight.

So, that's from the research standpoint, but for care of patients who have dementia or Alzheimer's disease, families are the ones who are going to recognize that the delirium is happening, so I want to be able to train family members and caregivers to recognize the delirium, to spot it early, to also know how to prevent it. And I think this is incredibly important and can make a huge difference for the millions of people suffering from dementia and Alzheimer's disease.

Dutchen: Oh, wow. Of course, not all cases of dementia will arise from delirium.

Inouye: Correct, correct.

Dutchen: But it could ...

Inouye: But if people do have dementia, studies have shown that 80 percent of them will develop a delirium at some time—

Dutchen: Oh, so it works both ways?

Inouye: Mm-hmm, at some time in their life, of their time living with dementia. So, if that could be prevented ...

Dutchen: Mm-hmm.

Inouye: We also know that delirium accelerates cognitive and functional loss in people with dementia. And so if we could prevent that from happening in 80 percent of dementia patients, that's just huge.

Dutchen: Yeah. Well, in another 10 years, say, we'll have you back on the podcast and we'll have solved this problem too. What do you say?

Inouye: That sounds great. I'll look forward to it.

Dutchen: That is all the time we have, but thank you so much for being our guest today.

Inouye: Thank you, Stephanie.

Dutchen: This has been amazing.

Inouye: Yeah.

Dutchen: Listeners, if you want to find Sharon on Twitter, she is @sharon_inouye, I-N-O-U-Y-E. Thank you all out there for listening. Thank you, Sharon, for being our guest today.

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