PANS/PANDAS 101: What Every Parent Should Know About Sudden Psychiatric Shifts Transcript

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Introduction to PANS and PANDAS

This is Dr. Talks. Genetics can open the door to understanding what's really going on beneath the surface. At Hope for Healing, we used advanced genetic panels through our partnership with Begron to uncover the factors that drive brain inflammation, mood changes, and immune challenges in children.

This insight helps us move beyond quick fixes and create care that's truly personalized. We're thankful for Fagran sponsorship of this podcast and for making this kind of root cause medicine possible. Learn more in the show notes. Hi, Dr. Kay. Thank you so much for being here.

This is an episode that I know has been, or this kind of content in general has been something that has been asked from us frequently, which is more information about pans pandas or man, I just wish I had the resources of walking through what it looks like to find the diagnosis, what it looks like to kind of be at the beginning stages of the diagnosis and how to really see and run into remission. So I'm so glad to be diving in with this. Thank you for being here.

I'm very happy to be here to talk about this. It's near and dear to my heart too because two of my four children have been affected by this. Because you are a parent who has seen the effects of Pants-Van is we're definitely going to be touching on a lot of that. So thank you. for starting that. Before, just in case someone is listening to this episode who has never heard of PANS or PANDAS, can you explain in simple terms what PANS or PANDAS is? Okay.

PANS is an acronym that stands for Pediatric Acute Onset Neuropsychiatric Syndrome. So acute means quick or overnight. PANDAS is pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections. So when we think about strep, strep that causes strep throat.

And that can also, and a really easy way to think about it is, you know, when you get strep throat, if you don't get treated, you can have an autoimmune attack on the heart valves called rheumatic heart disease. So when I first heard about this about 10 years ago, that's how someone explained it to me that instead of it attacking the heart and doing damage, ah it attacks the heart valves, then it can cross the blood brain barrier and attack part of the brain. And the part of the brain that tends to be affected is called a command and control center that's called the basal ganglia. that controls mood, appetite, movement, bodily sensations. You might hear things, see things. So that's the acronym name for it. Okay.

So I love that you started out with saying both it's pediatrics. So does that mean it only affects kids or can adults like have it and just not have known that they've had it?

Can you talk a little bit about that? Yes. ah You know, if adults have parents who are alive, they can kind of reflect back and go, you know, you have those things. And then an adult too, when they're exposed to it. So PANs, even though it says pediatric, the age of onset can be any age, meaning even an adult. But for PAN does, the strict diagnostic criteria say age three or above. In my experience, the youngest that I've seen pandas is one year of age.

Symptoms and Diagnostic Clues

had a parent, a grandparent asked me, have you ever seen a one-year-old all of a sudden be afraid of the bathtub? And my question was, does anyone in the family have strep?

And she goes, oh my gosh, the child's mother does. And sure enough, the one-year-old did too. So ah I think the criteria need to be adjusted because clinically we see something different.

So, I love that. and that, okay, that kind of helps understand. that's a little bit about the differences between PANS and PANDAS. Is there any other differences that we should know of when hearing about or learning about PANS and PANDAS? Well, when this was first discovered, it was a doctor that was working at the NIH. Her name was Dr. Sue Swedo. And to present something to the medical community, She presented very strict diagnostic criteria.

It is much more common to see, because this is brain inflammation, so we talk about encephalitis. And I don't know about you, but when I hear the word encephalitis, I think of a person laying back with a fever of 104, hallucinating and sweating. But you can be walking and talking and going through life and have profound brain inflammation and not stick the strict diagnostic criteria. So Lauren, what was your original question that I started to ramp up on? No, but it was just so good. think before we go back to my original question, which is fine, but I think it is super important to understand because what we'll get into later is that the symptoms are very, can be very dramatic and can be very scary, can be very overwhelming, but it won't look like what we expect. And so I think that's why we get into this. But it was just the question of what we should be aware of when the differences between pans and pandas.

Yes. So pandas is a subset of pans and it has to do with strep. And you tend to see more ticks with it, like movements, but We'll go with what these look like in a little bit.

love that. Yes. No, that's actually really great. so, and then, mean, honestly, what you just said is a big leading question to this, which is why do we feel like these conditions are often either misdiagnosed or not even looked at at all? Well, there's a lack of understanding and a lack of belief. And until many times until You see a child that this happens to, like a pediatrician. You've known a child for years and all of a sudden they come in with overnight onset obsessive compulsive disorder, unrealistic fears, not wanting to wear their clothes. It's, it's drastic, but there's also a very subtle kind of waxing and waning presentation where these children and or adolescents and even adults. get missed and it might get uh chalked up to social anxiety or, oh, they're just stubborn oppositional defiant disorder.

Right. Or it's ADD because they have trouble paying attention. So it can present many different ways and we can unpack that together. Well, and that's exactly what I'd love to unpack.

Because there's a couple of things that you're saying that I think will be really helpful. But before we dive into really getting into the weeds of that, can we just talk about some of the first signs or symptoms a parent might notice? Because I love that you mentioned that it's acute, meaning like it will feel like this overnight sensation, just like you were talking about with the patient. Like all of a sudden, there was this fear of water and there was this sudden change. and being able to pay attention to those sudden changes in our children. So can you talk a little bit more about the signs and symptoms? Yes. So basically, it's an abrupt overnight or very quick onset of obsessive compulsive disorder or really severely restricted food intake. That's the hallmark of PANS. But then you have to have two of the following seven symptoms. And these are behavioral and neurologic, and they occur pretty quickly too. So one of the things that I hear very much, it's like anxiety, but also in little ones, separation anxiety, where a mom cannot leave the room or a father can't leave the room. You can't go to the bathroom. You can't take a shower without your child right there. Now that's a little different where you're a mom and you just wish you could go into the bathroom and pee alone. oh right. But this is different. This is like this profound fear. And when you ask children that are old enough to kind of articulate it, many times they're really embarrassed about it, but you say, I ask, now I'm gonna ask you some questions and I don't want you to feel embarrassed about… what you're gonna say and you may not have told your mommy or daddy about this, but I wanna know, are you afraid that your parents might die? Do you feel like you have to be in the same room with them? And so many times they'll say yes. Now that's one of those seven symptoms. The other is emotional ability or really profound mood swings. Like go get your coat and they throw themselves on the ground.

gonna get my coat. It's just ridiculous. And it's not characteristic for your child or depression, like this sadness, this blackness. A lot of times these kids will journal very dark and ugly things. So those are the first two of seven. The third is irritability, just over simple things, profound aggression. and or severe oppositional behaviors. I mean, there's, it's just like, no, I'm not doing that. Or they're like in your face and this is not your child. And then the next, and sometimes this can be profound and it's been seen in adults, it's behavioral regression. Like an older child beginning to talk, baby talk or sucking their thumb. That has even been observed in adults. Okay. Which is. crazy,

then a sudden deterioration in school performance. And one of the things that we ask children for are handwriting samples.

So sometimes you'll begin to see these are kids that can do copywork and stay on a line. Well, they start going down the page. And then also, and I observed this with one of my children, her schoolwork, she was drawing an eye, the dot on the eye. I said, Honey, do you feel like if you don't fill in that eye over and over again that things aren't gonna be right?

So an obsession is you're thinking about something and focusing on it. A compulsion is where you have to do something in order to feel an emotional release. I like that. um Then one of the other is motor and sensory abnormalities. So you might have a wide-based walk. um A child might start steering into the wall. And as far as sensory, they may literally have hallucinations. They may be seeing something. They may be hearing something. But they may also feel like something's on their skin. And then lastly, somatic signs and symptoms, including sleep disturbances, bedwetting, and peeing a lot. um what do those things mean? Feelings and sensations in their body that cannot be explained by anything else. So a lot of times these children can't stand tags in their clothing. They don't want to wear underwear.

Brain Inflammation and Triggers

They don't want to wear socks. um You can't explain the signs and the symptoms based on anything else. So if someone comes to me and they're hallucinating or um visually or auditorily, I'm going to get an MRI of the brain immediately. And I'm also going to get an EEG to make sure they're not having seizure activity or they've got a brain tumor. Or you need to determine the age. can even have em tumors in other parts of your body that has neurologic tissue in it, like a teratoma, can cause someone to have sensations. So you have to use good medicine, but it's a clinical diagnosis. That's PANS. Okay. So I really love that you dove into all of this. And so I think there's a very important statement that I want to make before I dive into this kind of line of questioning is hope for healing. are big, big, big proponents of mental health and having counselors and having psychiatrists. We are not anti that. But I really do want to ask some questions that I think are really important that are, do you think that sometimes it can be misdiagnosed because we write things off as behavioral issues or we don't really look into the adaptive? We just are like, oh, well, he's just a defiant child or she just can't like… I don't know, you kind of talked about this a little bit in ADD, that we are so quick to label people in general, but specifically children on their abilities, that we may not dig deeper. Yes. Everyone wants to label something. And many times those are, the child or the adult may meet the criteria for that diagnosis. But if it's there with these other symptoms, You have to explore more. So for example, eating disorders. In my practice, every single person that's come to us with an eating disorder meets the clinical criteria for brain inflammation. And many of them meet the strict diagnostic criteria for either pan's, pan does. Okay. That's frightening. And these individuals are then exposed to foods and it's like all about having a good relationship with food, but we're giving them inflammatory foods, whereas we're not asking why they have a body image distortion to begin with. Why do they think they're fat or, or the other is there's an eating disorder called RFID, which is avoidant restrictive food intake disorder. Everyone wants to give a label to it. And so the severe restriction, but also just the texturals, you know, a lot of children that are in feeding therapy have pans-pandas. A lot of children placed on medications and labeled as bipolar, they have pans-pandas. They're not bipolar. And then when you get a family history, oh, grandma, grandpa, but then when you go back, you go, they had strep, they had mono, they had all these things. Influenza A or B that triggered this or hand, mouth.

So yes, you are exactly right. And I believe that you use all the tools in your arsenal to help someone get better. So if they need an anti-psychotic or they need a mood regulator, a mood stabilizer, or an anti-anxiolytic, we'll use it. If that's what's going to help. but you also don't want to um what's happening with um cover things up with medications. Well, and that, and you know, that is actually a conversation I have with parents all the time where they have found something that temporarily will, or even a little bit longer than temporarily provide relief. for their child, but ultimately are coming because they're like, this is fine for right now, but I don't want this to be my child's life forever. Or even like adults that will come to the practice that go, hey, I'm coming with this medication. Like, are you gonna rip this out of my hands? And you're very quick to go, no, we like that it's providing you relief, but what we're trying to figure out is the why. And you again, my favorite statement, I think you said this, you say this a lot. But it was really impactful the first time that I heard it when like we had just started getting to know each other and I've been with the practice four years now. And so it was that you said that ADHD is not a Ritalin deficiency.

Our headaches are not a Tylenol or Ibuprofen deficiency. We are trying to figure out what it is that's causing it. But when we need those medications in the process, you are not going to be like, No, you can't have what's giving you relief. And I really appreciate that balance you come to the table with um and just to be able to help people. And so I never thought about it from here, but this is awesome. That can be extremely dangerous because, example, taking an SSRI, selective serotonin reuptake inhibitor, if you pull that away, a person can get serotonin syndrome and die. it's you need… to approach things in a very intelligent sequence and do a very complete physical, obtain a really good history and um move on from there. I love that. em So before we dive into some of the triggers and what's actually happening within the body a little bit more, can you talk a little bit more about what you're talking about, the waxing and the waning of these symptoms? And so because it feels acute, right? So it feels sudden, but the waxing and waning could make things a little bit difficult.

So could you talk about that? Yeah. So because this is an inflammatory process in the brain, and this is something we're going to repeat, uh inflammation, think about something that's hot, red, swollen, and painful. Well, if the child's brain is hot, red, swollen, and painful, they can't unzip their brain and say, look, mommy and daddy, my brain is inflamed. But how does that manifest itself? Temper tantrums, sadness, an inability to sleep. And we all have good days and bad days. So good days when the inflammation is lower, bad days when the inflammation is not. Now, if you have an infection that's smoldering in your body and you treat it with antibiotics, you get better. But then what if you get that infection again? say in a reservoir like the tonsils or the adenoidal tissue um or another type of a trigger, a viral infection, and um you can continue to assault the brain and there can be damage. Okay, so I had mentioned that um Pandas is associated with streptococcal infections, but there's the the same criteria as PANS, but a lot of OCD and or tics. And there can also be multiple and complex and unusual tics. And when you have strep, um there's something that's been recognized in the medical literature. um It's called Korea form movement. And what that is is like a snake-like movement, like moving the shoulder. or moving the neck, it's worm-like movements.

And so in one of my children, this happened when she was uh one and a half, two years old, and we couldn't figure it out, but she was not one of these children that would settle, but she would do this. And then at age six, she got full-on strep with a rash, which is scarlet fever, and she developed almost overnight. a habit of pulling up her socks on each side and she would say one, two, three, one, two, three, one, two, three, one, two, three. She had to go around her room at night, all the little drawers or compartments where her things were, turn the lights on multiple times. And that is brain inflammation. And so the other thing, as we said, with pandas, The strict criteria is, three years of age that they're evident by. But as I said, that little one-year-old, ah it was overnight. And many times you'll see this acute onset, then episodic, relapsing, remitting, relapsing, remitting course. so um sometimes as far as some of these somatic symptoms that you'll see, you'll see this you'll have to pee. These kids will have to pee all the time, but they may not pee a lot, or they have this sensation that they have to pee. Their pupils are dilated. They're dilated upon exam. And the parents notice that too. That may be the only thing on exam that I see. And I've done this where I'll see a child for the first time. I notice that their pupils are dilated and I talk to the parents and they say, Yeah, we've noticed that we swabbed their throat. They have no fever, no redness, no pus in their throat, and they have active strep.

And the parents had no idea that, you know, there's no clue until you test. but that child was presenting with pretty high functioning autism. So brain inflammation. um remember you were actually talking to a patient one time that that was presenting, they were messaging us because they were presenting symptoms of a flare. And they were like, we have no idea what's going on. We've been doing all the things you had had. And they were kind of upset and panicking. And you were like, we need to get them in for a strep test. And they were like, no. And you were like, no, like, I promise you, like based on everything we're seeing, we need to get them in for a strep test. And turns out it was positive and they were even like, wait, hold on. Like, how do I even, like, how do we figure this out? And so it's very common.

And that's why I think I like about when people can partner with Hope for Healing and other functional providers that have that knowledge to go, let's go here, even if it isn't a duck, it doesn't waddle like a duck, it doesn't quack like a duck. But what we are seeing is because we know this other. pandas thing.

Environmental Illness and Susceptibility

We know the child had pandas already and the fact that they had strep, everything was coming back up. And so it was really cool to see the one that because you knew, because you had given them all the tools and the tool belt that we'll talk about later, they were able to get her back into a calm state and functioning so much faster than they would have. So it was really cool. ah I think it's very interesting that you bring that up because what were her presenting symptoms? uh This little girl had some neurologic challenges, genetic neurologic challenges. She has a syndrome. She came home from school and she soiled her pants and she urinated. And she was laying on the floor kicking and screaming and they're like, what do you think is wrong? And they lived far away and they went to, I said, go to urgent care. And she was positive. And that was the impetus for this family because she had no fever. She had no rash. It was only the behavioral manifestations losing bowel and bladder continence and throwing a huge fit, totally uncharacteristic. That's what prompted them to do the tonsillectomy and adenoidectomy. The other big thing that we hear is, all of a sudden, my child can't sleep, and we're like, get in here. And we'll do a respiratory panel. recently, ah It was a child who had a gut virus and then another child that had a respiratory virus that we were able to, it's a LabCorp nasal swab and their insurance covered it. We did her physical, we couldn't find anything else. So you never know. So you look at those symptoms. Let's dive a little bit into what's actually happening in the body and brain when a child has Pans-Pandas. I know you just spoke a lot about the brain inflammation a little while back about brain inflammation and how we em can't see brain inflammation when you're just looking at the child. um And so let's tie in how you were talking about brain inflammation and your desire to get MRIs and neuroquants and of the brain.

And so can you talk about… why we look at those things in brain inflammation and kind of tie those together when a child or an adult has pans pandas. um So inflammation being hot red, swollen and painful, and the only way that your child might be showing that is ticks or not walking straight or screaming or not being able to sleep. You must determine if they have an infection and it's not just one part of the brain. Yes, pans-pandas were focusing on the basal ganglia, but it's throughout the entire brain. And our brain is supposed to have this nice, tight blood-brain barrier. Well, the blood-brain barrier, by definition, when you have all these signs and symptoms, is not tight like it should be. So another simplistic way of looking at this is anything that could potentially cause a fever in a person whose immune system does work could cause this. oh And so this would be considered other types of infections that can trigger this that are not strut. Right. So this is the umbrella of PANS. So PANS can be caused by influenza A or B. PANS can be caused by COVID. PANS can be caused by Coxsackie virus, which causes hand, foot, and mouth, or sore throat. It can be caused by Epstein-Barr virus, which causes mononucleosis. It can be caused by this disease, which is slop cheek appearance.

um It's a herpesvirus family. It can be caused by herpes simplex virus one or two. It can be caused by cytomegalovirus. um And that's just uh one thing. It can be caused by Borrelia, which causes Lyme disease. It can be caused by Bartonella um from the cat scratch. It can be caused by Babesia, which can be caused by mosquito bites, flea bites, tick bites. would these be considered like environmental toxins that could affect this system? Or would these still be considered under the bigger umbrella of infections that just so happen to come from an environmental cause? Those are infections. Everything I came from out. Yeah. you know, you could go in the woods and your kid gets a bullseye rash that shows up on their scalp.

know, little kids walk close to bushes and you may not even know. So we need to rule all those things in or out, but it's a clinical diagnosis. So there's a website called the spire.care and it puts PANs and PAN does. You can read through that and there's not one specific test. for these things. Now there's really rare things like something called anti-NMDA autoimmune encephalitis. That was the documentary called Brain on Fire. It was about a young woman, 21 years old, that started going crazy. And she stopped talking and was almost catatonic.

They had her draw a clock face and it was just on one side and they did a spinal tap. They gave her IVIG. I have steroids and she's back. She's written a book, she lectures. But you get labeled as crazy. And also like skin picking. If you're, you know, skin picking, that's like a neuropsychiatric thing. I've even had a uh beautiful young woman at age 16, second in her class at a very large school here in the Houston area, dissociated and struck and attacked her mother twice. And mononucleosis was the trigger when blood work was done.

She's now thriving. She's a freshman at Texas A &M. But she had her tonsils and adenoid removed, and she's got her brain and her body back. So. love that. um OK, so everything that we had mentioned was infections. And is that always the cause? Or are there environmental toxins or immune imbalances that can play a role? in Pans Pandas.

am so glad you asked that question because here at Hope for Healing, we treat people for environmentally acquired illness, which is called chronic inflammatory response syndrome or biological toxin illness. So mold is everywhere, but if you're in a home where the humidity is too high, there's food for mold to grow. But inside the interior of a water damaged building, there's not just mold. but there's also gram-negative bacteria. I call it poopy water bacteria. Think about poop when your toilet overflows or another bacteria that um inhabits the skin and colonizes the skin called actinomycetes. uh In the community of chronic inflammatory response syndrome, there's Dr. Richie Shoemaker, Dr. Scott McMahon, Dr. Jimmy Ryan, and another naturopath, uh Jennifer Lewis, I believe is her name, from Arizona, did a retrospective study, and they've tried to publish this four times. But they took all the children in the practice that met the clinical criteria, diagnostic criteria, lab criteria for this chronic inflammatory response.

retrospectively, the majority of them met the clinical criteria for PANS-PANDAS based on their initial presentation. And so this has not made it into the entire PANS-PANDAS community.

There's a lot of excellent providers and we're trying to talk, but there wasn't a world expert on Pans Pans is the immune system neurologic manifestations um to peer review this article.

it's that so to go back a little bit for people who don't understand how all that process works is that they want to publish something but because there isn't an expert yet because this is new there isn't someone to give the stamp of approval for this type of review. Right. Right.

Hope, Advocacy, and Closing Remarks

But when I read through this these environmental things can make, they open up the blood-brain barrier and they open up the gut-blood barrier. So if you have this genetic vulnerability for this biological toxin illness, or you don't have the genetic vulnerability, but you live in a home that's severely water damaged and it oppresses the immune system, by definition, you've opened up the gut blood. and the blood-brain barrier. So, SERS is a precursor, meaning if you meet the criteria for chronic inflammatory response, biological toxin illness, water damaged home or school or car, you can develop PANS or PANTAS. Right. So, it makes you susceptible, is essentially what saying, is that… Now what might not have, you might get strep and that would not have been the cause, but because you have this susceptibility now, strep is now going to trigger a cascading of events. could, or one of those viruses. Yeah, that's right.

Whether that's a tick, whether that's a, okay. Or COVID, long COVID. That's true. Before we go off of this, what's really incredible is that they've shown this in a… a blood test that is measuring proteins from 177 different genes. It's called a genie. So Dr. K, a lot of this sounds really scary and overwhelming. um I think as someone who personally has had Lyme disease and has gone through the SIRS and the process, can make life, it can make it scared to do life. It can make it really scary to do life and to like live and exist.

What kind of hope for someone who's listening to these symptoms and going, that's my child or that's me? What kind of hope can we leave them with? em there is hope for healing, that there is something that they can do about it. What would you say? Yeah, well, awareness is the first part, but then getting a medical provider to believe you. And if you can't come to hope for healing, there's an organization called Panda's Network. There are different ways to treat, but I really love the functional medicine approach, which we'll unpack later on. But we blend everything and we do all kinds of things. So I would say number one, don't go into the pit of despair. Okay. But realize because damage is taking place and inflammation is happening, reach out to a medical provider. Now.

I want to encourage you, and I'm just going to be very vulnerable here. I remember when I was in sixth grade, I had mono and I had strep at the same time. And I had profound OCD and I had eating limitations, but I was the oldest of four children and there were a lot of things I never told my parents. But I made all these lists and I was obsessive and compulsive about it. I'm on the other side and I'm okay. So I had the pandas, the classic pandas. didn't, well, I didn't have tics, but I had a lot of the OCD and the sleep disruption. But I was in sixth grade. I didn't get my tonsils and my adenoid out, but I hit puberty and things got a lot better. And in fact, just at that time they were talking and they looked back, my dad was in the military, they looked back and I had 13 documented positive strep infections.

But no one talked about what my tonsils looked like. And when I hit puberty, when they started talking about it, I stopped getting strep infections. But then I started developing the environmentally acquired things with the migraine headaches, my jaw hurt, and all these other things. And so the SIRS went undiagnosed and the mono, you know, really wasn't addressed and the positive Lyme antibodies. I was treated with so many antibiotics, we think that that took care of it. But I would let you know that as a parent, you need to advocate, but you don't want to bully people. You want to reach out and talk to your pediatrician because there's a statement in the American Academy of Pediatrics saying that they believe it's an entity, but you need to look on that pandasnetwork.org and try to find someone that can help you. or fly to Texas and we'll take good care of you. Absolutely. You may need to stay a little while. Yeah.

Okay, so quick question for you before, because I think there's a couple of things you said in your closing notes that I want to make note of. How long have you been a doctor? Not specifically with functional medicine, but a doctor in general. I graduated from medical school 36 years ago.

Wow, that's amazing. Yeah. Okay, so then my closing statement to anybody listening… 35, I'm sorry, 35. You're good. You're good. So close. Is that if you are listening right now, you have a doctor who just said, you're not crazy. You have a doctor who's been a doctor for 35 years who has not only walked through their home children, has not only walked along sound patients, but have walked along this process herself saying, you're not crazy. And so if you have to fight and kind of she said, you don't need to bully people. You don't need to bully people to convince. If they're not listening to you, then move on to the next doctor. You have your, you have your right to be able to step into that. And so thank you, Dr. Kay for the vulnerability of you just sharing your story and just reminding people that if anything we are telling you in this episode, you're not crazy. Your child is not a bad egg or. um or having difficulties in the way, and we're going to get more into that.

So please, please stay tuned for the upcoming episodes about how we can have that discussion. Yes, Dr. Kay? I think another word of encouragement is you're not a bad parent because your child behaves this way. I love that. You're not a bad parent. No one's walking in your shoes in your house. They don't know what kind of a parent you are and what kind of modifications like. You may have a bunch of kids and you're like, well, that's just my kid. have to do this, but no, no, no. You're not a bad parent. You just don't know what you don't know. love that. Well, thank you so much, Dr. Kay. And I'm super excited to continue this discussion as what we look at in treating PANS Pandas, what the conventional approach would be. And it's going to be a great conversation. So y'all going to want to stay tuned. Thank you for tuning in to Dr. Talks. We hope today's episode has enlightened and inspired you on your path to optimal health. Each day is a new opportunity to make choices that empower your well-being.

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