



Episode 24: Osteoporosis – No Bones About It

Note: This is a machine transcription. Please excuse any punctuation or other weirdness:)

Intro:

What is a bone density test and who needs one? A bone density test measures how strong your bones are. They are recommended for all women age 65 and older, and for younger women at higher than normal risk for a fracture. Men may want to discuss osteoporosis screening with their doctor if they're over age 70 or at a high risk for thinning bones.

People tend to think that bones are static and unchanging, but the truth is that bones are in constant flux. Unfortunately, as people age, they often lose bone more quickly than they can replace it, so their bones can become porous and brittle. If left unchecked, this bone loss can lead to osteoporosis, defined as reduced bone mass and poor bone quality.

People who have osteoporosis have bones that can break with even the mildest impact, so it's a good idea to make sure you're building up that bone density. But how do you do this? Or maybe you're in a situation where you are already diagnosed with osteoporosis. What are your options?

Get Savvy...Demystifying Healthcare – 30 second commercial

Are you tired of the high cost of healthcare? Are you overwhelmed trying to navigate a complicated healthcare system?

Welcome to Get Savvy...Demystifying Healthcare weekly podcast where we take complicated healthcare topics and make them simple.

Imagine if you could stop feeling paralyzed with fear and frustration and instead be empowered to make smart healthcare decisions for you and your family.

Get Savvy with your host, Sandy Kibling, a healthcare professional changing how healthcare knowledge is shared.

What we will discuss:

- 1) Early diagnosis of Osteoporosis - Jayne's Story
- 2) Navigating the healthcare system to get the help you deserve.
- 3) Being your own advocate on your health journey.

Sandy

Hello everyone, and welcome to Episode 24 osteoporosis. No bones about it. We hope for good health every day, and staying on top of those annual checkups with your primary care physician is important, as well as preventative exams like mammograms and colonoscopies.

But what if you get a diagnosis like osteoporosis and you need to understand what your options are for care? I'm delighted to have Jayne Wesler on the show today. Jayne is an author, Psychotherapist and Attorney.

She's the author of 8 books, including 3 books on increasing bone density and bone health without medication. After publishing her first bones book, Jayne started a Facebook group dedicated to helping people with osteopenia and osteoporosis to learn how to strengthen their bones and prevent fracture.

I'll make sure and add a link in the show notes for this group and other amazing resources Jayne has provided.

Jayne welcome to the show.

Jayne

Thanks so much, Sandy. It's great to be here today

Sandy

You and I talked initially about your journey through the healthcare system once you were diagnosed with osteoporosis at a young age, and the frustration you encountered and how you uncovered your own way to address your condition.

I was hoping to unravel some of this today and was hoping you could start by telling us your story.

Jayne

I'd be happy to do that. I think unraveling is a great verb and it's a great way for people to look at things and for your audience. Just think about that.

Think about unraveling and we're going to get into that. I have always known that I was at risk for developing osteopenia or osteoporosis.

Jayne

As a young woman, I had a number of the risk factors. That's really important for people to know what the risk factors are, but that's going to be part of your own unraveling out there if you're listening. So I took precautions. Ever since I was in my early twenties I ate well, I had good nutrition, always. I exercised a lot, including weightlifting and running.

So I was surprised that on the commencement of menopause, which is when you first get your first DEXA scan that my doctor, whom I've known for 30 years, came into the room to give me my results and he was bug eyed. I realized later after I got over the initial shock, that he was shocked. He didn't expect to have bad numbers on the DEXA scan.

So he kind of gave me his approach about what to do and how to address it. It was very odd because he was telling me to walk and I was so far beyond that already so he told me to take calcium and vitamin D, and that's pretty much the blanket advice that women are told initially if they're diagnosed with osteopenia or even osteoporosis, that's what you do.

You take calcium and vitamin D, unfortunately, that's not the whole story, but it's not what we're told. So I had a couple of DEXA scans, you get them every two years and at age 54 when I met with my doctor post DEXA scan, he said to me your bones are thinning at an alarming rate, but he was not proposing to do anything different.

Also, he was going to wait 18 months and then do another DEXA scan. I thought, wow, that sounds crazy to me because if they're thinning at an alarming rate, will there be anything left, in 18 months?

I really pressed him for a while and asked a lot of questions and I think he got exasperated and he finally laughed and said to me, well, I don't know, eat more ice cream.

I left there feeling very much on my own and in the years since, I've discovered that a lot of women and even men, because men can get osteopenia and osteoporosis too, have felt this way...confused, alone, terrified.

I came away thinking I have to find my own solution. Thus Sandy began the unraveling. I'm a psychotherapist and then later in life became an attorney. As an attorney, you have to examine evidence for credibility, and so this is what I brought to this endeavor. I read everything I could get my hands on...articles, books by specialists studies, very good studies, and I learned so much, but it was under quite a bit of duress and people don't need extra

stress in their lives. Many of us are running as fast as we can, and that's partly what makes us sick, right? The chronic stress, but then to add on top of it the fact that you think you have to find your own answers

Sandy

You know, can I pause and ask you just a couple of questions if you don't mind. There are a couple of thoughts that came in as we've unraveling here. You talked about a DEXA scan and just for people who may not know what that is, do you mind from your own experiencing helping people understand what a DEXA scan is?

Jayne

Sure and thanks. A DEXA scan is a scan that you get of your bones, not your entire skeleton but usually a couple of points like your wrist, your femur and your total hip and your spine and that it, it's DEXA stands for Dual Xray Absorptiometry and so it looks at the density of your spine, now that's actually it looks at the quantity of your spine, not the quality of your spine.

A DEXA scan is usually performed when a woman enters menopause and continues thereafter for a number of years every other year. It's meant to assess a woman's likelihood of fracture, but unfortunately it doesn't actually give us a good picture of who's going to fracture and who doesn't. There's a whole industry behind this, but that's essentially what a DEXA scan is.

It is important, they say, to have a DEXA scan done in the same facility on the same machine and even by the same technician if possible, because that reduces the likelihood of an incorrect reading. So that's what a DEXA scan is.

Also other people can get DEXA scans, for instance, if you've had cancer, if you had breast cancer, or if you've had other kinds of diseases like some kind of gastrointestinal disease that like celiac disease or Crohn's disease, something that has messed with your gut to prevent the assimilation of nutrients so a number of people, categories of people, might be set to have a DEXA scan at one time or another.

Sandy

You know what I find interesting as you were talking about this as well is that and I'm post that menopause phase but I have never had a DEXA scan. I love when you talk about being an advocate because I fall in that criteria where I should get that done but I've never asked about it.

You almost have to be your own advocate and request that because it's never been offered to me to do that. So I think it's about being your own advocate and really finding resources and talking to your physician as well because you know, having that knowledge and getting that test done obviously is so important as it's proven to you.

Jayne

I think it's an important test, but on the other hand it can send people into a pool of fear and it can cause your physician to prescribe drugs for you that you may not need. So that's the ugly side of the DEXA scan. DEXA scans are notoriously unreliable. Maybe they're not notoriously. I should take that back. They can be unreliable and the percentage of unreliability varies a great deal. So anybody who's going to have a DEXA scan really needs to understand that the emotional impact of a DEXA scan can really set us up to be vulnerable to a physician's suggestion that we take medication.

It's really important to know probably ahead of time before going in to get a DEXA scan before getting the result of your DEXA scan. What all that is about? I do have a video that people can watch. It's on my website at jaynewesler.com. There's two free videos actually and there are many resources as well, but there's a video all about osteopenia and osteoporosis, and I do talk about the DEXA scan. One thing that the DEXA scan traditionally has not tested or assessed is trabecular bone score and we don't really hear about that. We hear about Bone Mineral Density (BMD), that is the quantity of your bone and certainly we want to increase the quantity of our bone when we can. It's best to do that naturally because if you take medication it's unnatural and it may result in brittle bone, it may be spongy bone, it may be steady stagnation in your body caused by the effect of the medication. We also need to be concerned about Trabecular Bone Score (TBS) and that's the quality of your bone and the DEXA scans have not tested that.

There's another technology that has come to us from Italy called the ECOLYTE scan will test your bone mineral density, but it will also test your trabecular bone score, and that is the strength of your bones. That's really important and people need to understand in order to be your own advocate. In order to avoid the risks of taking medication that you don't really need to, it's important to understand the reality of the efficacy of the medication and whether or not you need that medication.

Sandy

Great information. Going back to when you were talking about the physician saying we'll do another scan in 18 months. That would be alarming to me if the numbers came back as you stated and setting you on the path to seek out alternative options. What was your next step on that once you said, no, I'm not going to wait 18 months. I'm going to, be my own advocate.

Jayne

I was forced really to be my own advocate. I guess I could have waited 18 months, but that didn't seem like a great idea. So again I started researching and investigating and kept learning and learning and learning about what other vitamins and minerals I needed and began to incorporate those into my diet and took supplements.

Instead of doing a workout on the Stairmaster or the electricalical trainer, I started walking a lot and instead of focusing on cardiovascular health so much I focused instead on striking the pavement. I used to run a lot, but I stopped running for a variety of reasons. If you walk you have to pay attention to how often you do it, your frequency. How long you do it and your duration and the intensity of your exercise.

It is important to do exercises. Walking is an excellent exercise. It can strengthen your bones. So I started to walk a lot. I continued to do weightlifting. I also investigated what else I could be doing and I asked my physician for a referral to Physical Therapy (PT).

Now I think back then I needed a referral. Tell your physical therapist that you want a regimen, to strengthen your bones, and that's what I did. The physical therapist, was open to this and it didn't seem to throw him off, like as if, oh, this is really strange, this seems to be a normal thing to do, and yet no one had referred me to go do it.

I went for a couple of weeks and did all the exercises and then he said, you know, you can just do this on your own. So I did the regimen every single day, doing that on my own, and found some other things and just incorporated a variety of those into my daily and weekly routines.

Also, I kept seeking specialists because I thought somebody has to have the answer out there. I have to find the answer. And I thought, you know, I would almost go anywhere in the world to find this answer. Yet I wasn't finding anybody who really seemed to know the answer. And there are people who say they specialize, but I was getting a lot of people who are just prescribe medication and I didn't want to do that.

I felt that was a last option for me because I knew I had researched that and I knew that option came with risks.

So after about 11 months I had seen a Rheumatologist that was very well respected. I was about to go and see an Endocrinologist, and then, lo and behold, a colleague of mine called me up this very same morning and said you need to see this doctor.

Long story short, through a variety of coincidences, I was actually able to get in to see that this other new Doctor who'd been recommended to me. A week later I had gone to the Endocrinologist and I loved her, but she wanted to put me on medication right away. So the new physician recommended by my friend assessed me. I told her what I was doing. I said listen, it's been almost a year. I want to get another DEXA scan. I'm not going to do anything until I get a DEXA scan and compare it to last year's DEXA scan to see if any of these interventions did any good.

She said. Great, that's what we're going to do. The insurance company didn't want to approve another DEXA scan or pay for it so they said, oh, you can only get that...you know that person on the phone just reading a script to you, right. So you have to advocate. So the way I advocated there was, said I was gently, kindly, persistent and she said, oh, you can't get a DEXA scan. It's only been a year.

I said, well, my physician is ordering one for me and we had a little back and forth and then she said. Are you being treated? And I said yes. What she meant was are you taking medication? What I meant was I've been doing a whole lot to change my bones. So she said oh, okay. So I got another DEXA scan.

I was really afraid to look at the results and they came through a portal where luckily I was able to get the results early in the morning. I was leaving for work around six thirty and I saw that they had come in and I just froze for a second and I said no, I have to look, and I have to be brave and look at these results.

To my surreal surprise, Sandy, I had increased my own bone density by 11.3%. It was just so hard to take that in. Like, is this true? Did I really do it? And the answer was yes, I really did do it. I didn't need medication. Now it took a lot of work and dedication and time to get to that point, but it can be done and you don't need to increase your bone density that much but people can do it and there are ways to do that.

Sandy

A couple of things came to mind when you were talking and I think about in my role on a day to day basis. I'm physician consultant, so I work with physician groups nationwide renegotiating their contracts with health insurance companies.

I often feel so bad for providers because in our healthcare system they're paid on quantity of care and not quality of care. So when you hear comments like we'll see you in 18 months and I'll prescribe this medication...I don't think it's an uncaring provider at the end of the day, as much as they're having to run to that next visit or just provide options to move to the next patient. I loved how you just said that's not for me.

We know everybody's different and everybody's going to make their own healthcare choices that they're comfortable with but remember to be your own advocate.

I also loved your comments on the DEXA scan when you talked about getting that prior authorization and being gently persistent. Be an advocate for yourself, if your health insurance company is 'denying a prior auth for a DEXA scan, you can take it up a level and appeal and ask your physician to have a peer-to-peer if that needs to be done as well.

Just for listeners out there it is important to know that a peer to peer is an option where your physician can meet with a physician from your health insurance company and discuss options.

I really appreciated that you were not going to just accept one answer. What amazing results you were able to get. Now you talked about walking and taking different minerals and stuff as well to kind of accomplish that goal. Do you think that was the key there and are you continuing to see improvement?

Jayne

So I have gone up and down in my bone density since and I think it's a direct result of after that DEXA scan where I saw the improvement of saying I don't need to work this hard because it was hard work and it takes dedication and we have lives our live.

I'm so much more comfortable now understanding that there is a whole world out there of choices. There are ways to increase your bone density and I'm not likely to fracture and I'm going to keep working at this. What was really neat was so after I got that terrible news and was trying to figure out what to do and how to do it, little by little I would lie in bed at night...you know, just almost rigid thinking about all the people, women, mostly women out there, who are being told you have to take medication and not being given options.

You mentioned that it's not an uncaring world of physicians and I absolutely agree. In fact, I loved my doctor. He is a wonderful person, but it's a world of Western medicine where doctors prescribe medication and do surgery, so it's important to find the right doctor for you. Some will put you on medication right away and other doctors will tell you not to take medication.

I wrote the first bones book, *No Bones About It*...increase your bone density without medication. I started a Facebook group because I had been thinking, how am I going to reach all of these people? And I thought, let me give this a try because I had all kinds of ideas. What a Facebook group. Ever since then, and it's been 2 years just past the two year anniversary and I have thousands of people in that group and more and more people asking to join it every day.

The cool thing is that I learn things too. I learn things from the people in the group and that's how I found OsteoStrong, which is an innovative technology to increase bone density. I found a lot of women who were being told you have to take this medication and there didn't seem to be a uniform quality of when doctors would say this or not.

There are such mixed messages I know my dentist was the one who said, please, please don't take bisphosphonates. And I said to him, don't worry, I don't plan to. I've been seeing him for decades and really trust him and he said to me, I can tell you I have seen people come in here who've been taking bisphosphonates and their jaw bone gets spongy, their teeth get loose, and they lose their teeth, which was pretty interesting to me that he would mention that.

So here's, a medical person, a scientist who has a thirst for knowledge. He goes to all kinds of continuing education all the time and he is telling me don't do this. I have discovered there are plenty of doctors out there who write about and talk about the other side of medication for osteoporosis. It's a matter of educating oneself before making those decisions.

Fear can be a driving force, and it can lead us to make sudden decisions when we're in a panic and we don't to be doing that.

Sandy

No, we don't. I often talk about the provider and the patient relationship. We put the provider in such a seat of trust and they deserve that, but it's a relationship. It's about asking questions or asking about alternatives. We talked a little bit about Western versus Eastern medicine. It's also okay to say that if you're seeing a provider and you feel that appointment is rushed or the recommendations aren't in line with your values it's okay to ask questions and or to find that provider who has the same philosophy as you and get a second and third opinion.

You're the one that has to live with the outcome and you want to know what those repercussions can be and what alternatives there are.

You mentioned fear and I think fear is such a driving factor, but you know we've said it many times in this show...be that advocate and continue asking questions and being open.

Also if you're not comfortable with taking medication, evaluate what are my options, ask questions and seek resources. That becomes so important in anyone's healthcare journey, whatever it may be.

Jayne

Yes and it's important for people that to hear it from you. I had a professor in law school who used to say hear me now and believe me later. I hope people are hearing this and internalize that you do have options and that's really important to understand that if your physician is not listening to you, then it is not a joint team and maybe it's time to try someone else.

There are women in my Facebook group who've said to me, my doctor said and they share with me their DEXA scans, their results and they weren't that bad. There was no need for panic or fear. The doctor had literally said to them, you either take this medication or I'm not going to treat you anymore. It's a form of blackmail. I don't understand that kind of thinking and if anybody ever said that to me, I'd say nice knowing you. Thanks so much.

There are doctors out there who really care. You've got to hand it to them because the environment in our country, it's a capitalist country. Well, so in the United States it is. And I'm sure you have listeners from all over, but it's a difficult world and physicians have a difficult job to do. It's very stressful and it's so nice to meet physicians who really care and who will talk to you and listen to you.

I've been hearing about a fairly new area of medicine called functional medicine or lifestyle medicine. They're actually two different ones, sort of overlap I think, where there are physicians who perhaps aren't happy with the way things are done here in this country and so they're looking for something a little different.

They're getting more education in that area and that's a good thing because it's going to help people who want to advocate for themselves, who want to be part of the team, who want to be as healthy as possible in the most natural way instead of just taking a drug which is going to have side effects.

Sandy

You know I appreciate that you mentioned that, back to my days when I worked for health insurance company I got to meet some of these groups that did practice functional medicine and appreciated there were different options for consumers to choose from.

I met with one functional medicine physician and I appreciated that he was taking more time with his patients. He was doing some preliminary tests and really taking that consultative approach and understanding where that patient was at and their goals and making sure to focus on, what was needed, for that patient's current needs.

I believe it is really important for people to know that it's just not a standard rubber stamp approach. There is also the Direct Primary Care model, which is a relatively new option, I actually cover that in a podcast. These physicians don't take insurance and consumers pay on a monthly basis which may be a more affordable option that works for some consumers.

Sandy

I would love to hear more about the Facebook Community group. I'm always amazed when people connect and share knowledge. One of the reasons why I started this podcast was knowledge is power, and sometimes it's really all that we have.

You mentioned researching and really looking at options so I appreciate that you've created this community where people feel like they can reach out and get answers, and you've mentioned you've learned some stuff on the way. I'd love to hear more about that group and I will provide a link to it in the show notes.

Jayne

The group is comprised of men and women from all over the world. A lot of them have passed menopause and are older women from say 50 to whatever who are dealing with bone loss and. Bone loss happens within, I believe the first three to five years after menopause. Women lose a lot of bone and then it stabilizes men begin a little later, because they don't have that sudden loss of hormone, but theirs starts more at like age 70.

So in the group we have a variety of people again lots of women and men in that age group, but we also have people who are were younger. I'm looking at these people every day and vetting them because you know as the group administrator I have to be careful about letting people into the group who are going to try to prey on people and try to sell them things, try to sell them services. So I am safeguarding the group against that. The group was actually public for a while because I wanted people to find it because I wanted to help people. One of the group members, private messaged me and said, you know, I'd be sharing a lot more if you would take the group private. I took a poll in the group and said listen some people have approached me with this idea and. I got a lot of responses saying go private, go private. So I did.

I'm learning and growing with the group. In the beginning, this woman said to me, oh, here's how I increase my bone density by something called bio density. And I thought, what is that? And I asked her to explain and it's like a facility that you go to and it's now called OsteoStrong developed by this Doctor John Jack who was trying to figure out how to help his own mother with her diagnosis. I learned alot and I started to do that and i actually have a webinar about that on my own website.

I hear what people are struggling with and try to come up with answers. I post in there about everything that goes into good bone health and it's just a great way to reach a lot of people. I'm encouraging people to talk to one another and that's really beginning to happen more and more so. It's really a pleasure to do that and a great way to advocate for people who are struggling with a variety of things. I'm sure that there are Facebook groups and perhaps people already belong to them for whatever it is that you're dealing with and so I would encourage people to make use of social media.

You have to absolutely protect yourself if you're going to do that and be careful about what you share online. But there's a lot of people out there and you're not alone and even during what is I guess the post COVID era where we are maybe more cautious about where we go and what we do. You don't have to be alone and there are ways to connect with people and facebook groups are one of those ways.

Sandy

I appreciate you having that group and opening yourself and sharing your story because I do think people may feel alone or it seems such a daunting task to seek help with busy lives and priorities. Thank you for creating this resource. You've shared a lot of great stuff today. I know that you've written a couple books and maybe just share some closing thoughts and also a bit about your books as we wrap up.

Jayne

I'd love to do that. The first book I wrote is *No Bones About It...Increase your bone density without medication*. That's the story of the first year and the things that I went through and what I learned. I thought it would be helpful and instructive and offer hope to people. I've gotten a lot of feedback from people reaching out to me for one-on-one sessions to help them to develop an individual bone plan, because it's really your lifestyle that makes the difference.

Everybody's different. We all have different risk factors and it's important to analyze your risk factors to identify them, and then develop interventions to counteract the effect of those risk factors. That's what led me to book number 2, which is about reversing osteoporosis and osteopenia without medication and with evidence based interventions.

Now I'm an attorney. I have lived and died metaphorically, thank God, based on evidence and credibility and that's what led me to write that book. I want to know what works. Bone develops slowly and goes away slowly, and we want to stop bone loss and we want to increase bone density. Bones send the signal to our bones...hey bones I need you to strengthen your cells. I need more density in there and there are ways that you can do that. I wrote that book to literally show what works and put the resources out there. I am not a medical person either but this has been my own personal journey.

I have learned so much that one of my doctors has asked me to come speak at the hospital where she practices because she said to me you're a specialist. That was her opinion, not mine, but there is a number of resources in that book and I tell you in that book what works to build bone density.

After I wrote that book, I felt that I needed to reach people online because people. It's easy to watch a video rather than to read a book sometimes, so I developed a webinar. I also did a four hour class once a week in one hour segments that can be found on my website where I take a deep dive into osteoporosis and how do we assess it? What are your risk factors?

Class 2 is a medication risk or reward. What are the medications? Each and every medication are the statistics that they put out there true or are they doing the lies, big fat lies and statistics? I talk about how to prevent fracture and what interventions that you can take to prevent fracture, because after all, that's what we're all really concerned about, if it might not matter what density we have or what quality we have of our bones.

We just don't want our bones to fracture. What really causes fracture and it's not osteoporosis believe it or not it's falling. So there's a whole a whole hour about how to prevent fracture and then the last one is develop your own individual bone plan and so the webinar and the course followed book number 3.

During my writing and development of the book and the webinar and the classes, I had this idea turning in the back of my mind because as a psychotherapist, I've always had to examine myself and I have never let go of that habit. I was thinking, oh my goodness, am I really eating right? Am I am I consuming the right food? Because there's so much. Evidence out there about that, and there's conflicting evidence. And that's what's so confusing, Sandy.

I decided to write a workbook. It's called feed your bones and a nutritional workbook for increased bone density and bone strength. I wrote it for myself and I wrote it for other people because I really wanted to reexamine what I'm putting into my body and that's important.

It's important for us to do the right things and take care of ourselves. It's also important to have fun and not worry too much about it. So we have to make sure that we get enough rest and reduce our stress because that those things go into factor into our bone health as well.

Sandy

You know it's so important and I think if anything that COVID has taught is when we were in lockdown is to slow down and really think about where we're at with our health. I have been on your website and you have absolutely amazing resources. I will make sure and link to all of those resources in the show notes.

I just want to say thank you for being a guest on the show today and sharing your story and perspective.

There are many different roads that we can take and it's just being open to that and evaluating options. You've given us so much to think about and I can't say enough about how grateful I am to you and thank you for your time today.

Jayne

Thank you!

Sandy

A great show with Jayne Wester and lots of education on Osteoporosis and the DEXA scan along with some valuable tips Jayne shared with us that she learned on her own journey.

I know that my sweet mom has had a few tumbles leading to a broken arm and two hip replacements. It can be devastating for them and the family trying to provide care and improve the living environment.

It's great to be proactive in building bone density to prevent these incidents. Make sure and check out the resources in the show notes.

In our next episode, we have Matthew Dickson on who is sharing with us his mental health journey and how he is helping others.

Until then, Get Savvy.